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"I know what it is but how bad does it get?" Insights into the Lived Experience and Service Needs of People with Early-Stage Dementia

By

Emer Begley

Thesis submitted to the
School of Social Work and Social Policy
Trinity College Dublin
in fulfilment of the requirement of the
degree of Doctor of Philosophy

May 2009

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DECLARATION

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Emer Begley

2009

SUMMARY

In Ireland, age-related illnesses such as dementia are becoming a greater policy concern in line with population ageing. Despite this, dementia-specific policies and practices are still largely under-developed and the preferences and thoughts of people living with dementia are rarely sought. This thesis provides insights into the lived experiences, the health and social care needs and service utilisation of people living with early-stage dementia. It links the 'personal' to the 'political' by placing their experiences within a framework of the Irish health and social care system, hence embedding the personal, lived experiences within the systemic context.

Taking a person-centred and Interpretive Phenomenological approach, in-depth interviews were carried out with 17 people living with early-stage dementia. In 13 cases, care-partners participated in a one-off in-depth interview. These interviews provided collateral information and gave insights into their own experiences of the dementia process. The third data source comprised of interviews with six policy experts; highlighting current policy priorities within dementia care in Ireland and placing themes raised in phase one and phase two of data collection within the present policy context.

This study breaks new ground in an area never previously explored in Ireland and it contributes to a small but emerging body of literature on dementia which is inclusive of the views of people diagnosed with dementia. Findings from the study show that the meaning of dementia for respondents was often the struggle to maintain self through sustaining existing roles. Respondents often used mechanism such as covering-up, normalising or withdrawing from social interactions to maintain this.

Many of the positive experiences reported by respondents were linked to relationships with family and close friends. Kinship networks were strongly linked to quality of life and were important for social contact, engagement and support. Respondents did not desist from

engaging in social activities with the onset of dementia. However, some respondents began to withdraw and participation decreased to facilitate and accommodate the dementia. Close friends provided valuable stimulation and care-partners reported that persons with dementia were often 'at their best' when in the company of others. This supports the conclusion that the provision or encouragement of social contact and engagement should be an element of any formal service development.

Other findings show that there are few formal service responses to people living with dementia. Even where services were available, the respondents were low service users. Reasons given for this were that participants (i) did not perceive their situation as critical enough, (ii) they never used social services before (iii) they did not know their current entitlements and (iv) there was a stigma attached to using social services. Findings provide valuable data on the lack of a relationship people living with dementia had with the broader health and social care system. The basis of this relationship can be broken down into: (i) the type of model that exists in Ireland (predominantly a medical model); (ii) incentives and currency needed to engage with services (physical ill-health); (iii) diagnosis (or lack thereof) and (iii) their relationship with service providers, which was often very *ad hoc* due to a lack of guidelines on best practice in relation to dementia diagnosis and referral.

Findings offer rich evidence of the issues people living with dementia confront in a system which provides inadequate and often inappropriate supports. This illustrates the resourcefulness and ingenuity many people use to manage and live on a daily basis with a diagnosis of dementia. These findings emphasise the need for formal services where the focus is on disability, rehabilitation and the promotion of the rights of people living with dementia as citizens. The thesis also makes several conceptual contributions and theoretical linkages, primarily in relation to the interaction between the 'micro' level of lived experiences and the 'macro' level of social and health care system characteristics.

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This thesis is dedicated to the men and women who took part in this research and to their families who supported them.

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List of Abbreviations

AD	Alzheimer's disease
APD	An Action Plan for Dementia
ASI	The Alzheimer's Society of Ireland
CDR	Clinical Dementia Rating Scale
DASN	Dementia Advocacy Support Network
DOHC	Department of Health and Children
DSIDC	Dementia Services Information and Development Centre
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders Forth Edition Text Version
GP	General Practitioner
GRAD	Guidelines for the Rating of Awareness Deficits
HSE	Health Service Executive
IPA	Interpretive Phenomenological Analysis
LHO	Local Health Office
MMSE	Mini Mental State Examination
NCAOP	National Council on Ageing and Older People
NESC	National Economic and Social Council
NESF	National Economic and Social Forum
OT	Occupational Therapist
PCCC	Primary, Community and Continuing Care
PHN	Public Health Nurse
PCT	Primary Care Teams
RTC	Randomised Control Trial
SDWG	The Scottish Dementia Working Group
UPIAS	Union of the Physically Impaired Against Segregation
WHO	World Health Organisation

INTRODUCTION

1.1 Background

This thesis investigates the lived experience and service needs of community-dwelling people living with early-stage dementia. This enquiry stems from the belief that a consideration and understanding of the lived experience of dementia is indispensable to shedding light on how people living with dementia can be appropriately and effectively supported to live and participate in the community. Findings based on information provided directly by people who have dementia can also be used to challenge assumptions and myths surrounding dementia. This enquiry places the lived experience of dementia within the context of the Irish health and social care system, thus linking the personal to a broader socio-cultural and policy system. Respondents living with dementia were placed at the centre of the research enquiry; they were acknowledged as meaning-creating individuals.

Age-related illnesses such as dementia have received greater policy focus in line with population ageing. Ireland has the youngest population in Europe with 11% of the population aged 65 and over, compared to the EU 27 average of 16.8%. Comparing Ireland to Italy which has the highest proportion of people aged 65 years and over at 19.7% (CSO, 2007: 11) we are still a relatively 'young' country in the European context. However, population projections indicate that between 1996 and 2011 the number of people aged 65 years and over will increase by almost 110,000 (NCAOP, 2001). With an increase in the number of people in older age groups, the number of people living with dementia will also increase. In 2007, it was estimated that there were approximately 38,000 people living with dementia in Ireland (O'Shea, 2007: 10). However, it is difficult to make accurate estimates, as not everyone receives a diagnosis and the above figure is based on population projections from the 1996 EURODEM statistics. These may under-estimate the number as the demographic profile of

the country has changed in the last twelve years. The number of people living with dementia could therefore be higher. Despite the demographic changes dementia-specific policies and practices are still largely under-developed in Ireland and the preferences and thoughts of people living with dementia are rarely sought. Now is an opportune time to plan and develop policies which will meet the needs of people living with dementia.

From the beginning of this investigation it was important that people living with dementia would be at the centre of the enquiry: this consideration led me to adopt a qualitative research design where people with early-stage dementia (N=17) spoke with me about the lived experience of the illness. They were also asked to talk about services they used and their experiences within the Irish health and social care system. Where possible, respondents' care-partners[i] (N=13) were also interviewed. Through interviews with care-partners, valuable collateral and contextual information was gathered. Another reason for including care-partners was the fact that dementia is rarely experienced in isolation; family members and friends are often affected and it was important that their thoughts were recognised and included. This thesis is also an enquiry into the broader context of the health and social care system. To ensure that a good picture of policy and practice was acquired, six (Irish) policy experts were also interviewed about the themes of relevance put forward by respondents in the other two sample groups (people living with dementia and their care-partners). This enabled me to place the respondents' concerns in the context of current and future dementia policy priorities.

In recent years there has been a heightened research focus on dementia and thanks to this, our knowledge of the complexities of the experience has increased and deepened. It is now recognised that dementia is a highly individualised and unique process. Cheston

[i] Care-partner refers to the person providing the greatest amount of support to the respondent. The term was adopted from Christine Bryden's (2005) book *Dancing with Dementia*. She has dementia and referred to her husband as her care-partner as they were approaching the illness together.

and Bender (2003: 91) state that "people experience dementia within a lifetime of experiences. Just as each of us is a unique individual, so every person will respond to dementia in their own unique way". This realisation has occurred in conjunction with an increase in autobiographical accounts of dementia and more original research that includes the thoughts, experiences and attitudes of those with the illness. It is important that these efforts to create a full picture of the experience of dementia continue.

A detailed examination of the lived experience of dementia has never before been undertaken in Ireland. We can learn a lot from similar studies elsewhere, but we must also recognise the unique cultural, social, political and economic context which influences the experience of dementia (see Chapter Three, section 3.11 for a further discussion of the policy and service context in Ireland). This is why a central component of this thesis is an analysis of the respondents' contact with the health and social care system. In the interest of appropriate policy development, it is very important to consider the views of those at the centre of the dementia experience i.e. those with the illness. Considering the views of people living with dementia sheds light on the service user context, which in turn can help in the process of designing and developing future appropriate services. This thesis therefore adopts Clare's (2002a: 139) view that "understanding how people with early-stage dementia naturally attempt to adjust and cope is an important starting point in developing interventions that can enhance self-efficacy and adaptive coping". Considering the lived experience of dementia and people's use and experience of the health and social care system in tandem offers the best chance of identifying and more appropriately meeting their needs.

1.2 Research Rationale

In Ireland most dementia-care research has focused on family and informal carers (Nolan et al, 2006; Ruddle and O'Connor, 1993); arguably this is because it is easier to elicit responses from respondents who are 'cognitively normal'. Froggart (1988: 131)

suggests that it "is part of the incipient ageism in our society that it is easier to identify with the carers than the sufferers. It is rather less painful and frightening too". Therefore, there is a need to move away from policy directives that take a 'caring for carers' approach and to move towards holistic user-led policy development that involves all stakeholders in dementia care, where the needs of all those involved are considered. This is one of the reasons why this thesis was undertaken; to explore the heretofore undocumented lived experience of people living with dementia in Ireland.

In the past, understandings of dementia have followed the 'standard paradigm' in the areas of neuropathology, biochemistry and the genetics of dementia, where X → neuropathic change → dementia, where X is a physical phenomenon (Kitwood, 1997a: 35). The work of Tom Kitwood, a British Clinical Psychologist, has been revolutionary in challenging the above school of thought. He pioneered the concept of Personhood in dementia care and argued that people living with dementia may be as much disabled in their experiences by public attitudes (malignant social psychology) and environmental psychosocial factors as by the neurological condition itself. Kitwood advocated a move beyond the bio-medical model of dementia towards a more psychosocial approach. The conceptual framework of this thesis follows the principles of his work by investigating the social aspects of having dementia (see Chapter Three for a further discussion of Personhood and person-centred care).

For many years, social research on dementia has been overshadowed by medical research. Clinical research is evidence-based usually consisting of large-scale randomised control trials. Psychosocial studies on the other hand, particularly those which include people living with dementia tend to be smaller in scale and in-depth qualitative enquiries. As a result, the contribution of psychosocial research to evidence-based practice is still at an early stage (Downs and Zarit, 1999: 85). However, the importance and contribution of an evolving community of social and behavioural scientists undertaking research that places the person with dementia

at the centre of the research enquiry should not be underestimated as they have significantly contributed to our understanding of the lived experience of dementia. To date many of these psychosocial investigations have focused on the self and self-awareness, identity, insight and ways of coping (see, for instance, Clare, 2003; Froggart, 1988; Gillies, 2000; Holst and Halberg, 2003; Howorth and Saper, 2003; Steeman et al, 2007).

Dementia-specific psychosocial interventions strive to improve and maintain people's quality of life. Combined with earlier diagnosis and the lengthier experience of the early stages of the illness there is greater scope for service-user consultation on the potential benefits of psychosocial interventions. It is also important to investigate what interventions people in the early stages are using (if they are) or what interventions could be beneficial for them.

Dementia is often seen as a 'wasting away' inside a (sometimes) still vigorous body (Shenk, 2001: 3). These negative images and portrayals of dementia are common; a person with dementia can often be treated as a non-person (Cheston and Bender, 2003: 76) and can experience a 'social death' (Sweeting & Gilhooley, 1997). But what are these negative images and portrayals based on? Are they based on assumptions of incapacity when a diagnosis of dementia is given? It is opportune then to focus attention on those who are in the early stages, where insight can be very high. It is hoped that identifying users' preferences for services will counteract this "social death", such as the withdrawal from social interaction and increased isolation which can be associated with dementia.

The public profile of dementia and the way it is perceived at a societal level also needs to be considered. The Alzheimer's Society of Ireland, in their 2007 'Manifesto', called for dementia to be made a national health priority. Anecdotal evidence suggests that dementia has gained a somewhat greater profile in recent years, as: (i) older people are becoming more politicised, their voices are now being heard at a higher level, (ii) dementia is receiving more coverage in

the media and in popular culture, (for instance in soap operas and in films), (iii) the population is ageing, (iv) there has been an increase in the profile of lobbying and voluntary organisations representing the interests of people living with dementia and their care-givers and (v) increases in funding resources for older people's services have encouraged dementia stakeholders to raise the profile of the illness. Given these changes and the renewed focus on dementia, it is timely to consider dementia-related policy and practice.

1.3 Prevalence of Dementia

There is a strong link between ageing populations and dementia as the prevalence of dementia increases with age. In 1996 O'Shea and O'Reilly applied EURODEM prevalence rates to the then most recent Irish census and estimated that there were 31,003 people living with dementia living in Ireland. Of these 18,345 (59.17%) were women and 12,658 (40.83%) were men. There are significantly higher numbers of women with dementia, in the main part this is due to the higher life expectancy of the female population. The projected growth in the number of people who will develop dementia is considerable. These demographics also show that early onset dementia, which is the occurrence of dementia in people under the age of 65 years, is increasing and it is estimated that this number will rise in Ireland from 3,429 people in 1996 to 4,931 people by 2026 (O'Shea and O'Reilly, 1999).

It can be argued that applying EURODEM demographics to make projections generates somewhat out-of-date figures. Ireland's demographic profile has changed enormously in the last twelve years as people are living longer and there has been a high level of inward migration. There have been no recent studies on the number of people living with dementia in Ireland and data presented in table 1.1 are the most comprehensive and most up-to-date figures available. Table 1.1 gives a breakdown of the projected number of people living with dementia in Ireland between 1996 and 2026.

Table 1.1: Number of people living with dementia in Ireland in 1996:

Age Group	1996	2001	2006	2011	2016	2021	2026
30-59	1,984	2,067	2,269	2,447	2,566	2,602	2,612
60-64	1,445	1,513	,1792	2,139	2,252	2,357	2,319
65-69	2,058	2,010	2,169	2,587	3,111	3,296	3,473
70-74	4,740	4,465	4,532	4,923	5,929	7,186	7,688
75-79	5,035	5,354	5,131	5,263	5,784	7,060	8,662
80-84	7,234	7,637	8,165	8,021	8,415	9,441	11,777
85-89	5,365	6,308	6,016	7,604	7,672	8,255	9,492
90-94	2,521	2,874	3,452	3,028	4,411	4,578	5,063
95+	621	562	690	839	985	1,115	1,179
TOTAL	**31,003**	**32,790**	**35,116**	**37,751**	**41,125**	**45,890**	**52,265**

Calculated by applying Central Statistics Office population data to EURODEM prevalence rates (O'Shea and O'Reilly, 1999: 43)

In 2005 the National Economic and Social Forum again applied the EURODEM dementia prevalence rates to the general population and estimated that there are approximately 20,222 females and 13,875 males with the illness (NESF, 2005: 87), which is an increase of 3,094 in less than ten years. Another issue is that to date little is known of the prevalence of dementia in long-term care in Ireland. However, the majority of older people, including those with dementia, live in the community: as a result, developing timely and appropriate community based dementia services is now extremely pertinent.

1.4 Theoretical and Conceptual Framework

The broad conceptual framework of this thesis can be characterised as psychosocial. This approach contends that an understanding of dementia requires a consideration of psychological and social factors, moving beyond the medical model of dementia. Kitwood (1997a: 135) states that a psychosocial model "does not pathologise people who have dementia, viewing them as the bearers of a ghastly disease...the new culture brings into focus the uniqueness of each person, respectful of what they have accomplished and compassionate to what they have endured...it emphasises the fact that our existence is essentially social".

Brooker (2004: 217) states that an element of person-centred care is looking at the world from the perspective of the person with dementia and that it is part of the phenomenological school of psychology. The theoretical framework and qualitative approach of the thesis is informed by Heidegger's phenomenology and is concerned with a contextualised position, it also adopts an interpretive component (Larkin, Watts and Clifton, 2006: 117). As such I followed an Interpretive Phenomenological Approach (IPA). IPA has its origins in phenomenology and symbolic interactionism (Brocki and Weardon, 2006: 87). I was interested in exploring respondents personal and lived experiences; how they made sense of their lives and how they applied meaning to their experiences in a form that is understandable to them. These are the exact characteristics Smith (2004: 48) describes as a likely study for the application of an IPA approach.

IPA, therefore constituted the theoretical foundation and procedural guide (Brocki and Weardon, 2004: 87) for this thesis. It can be described as having three broad elements: an epistemological position; a set of guidelines for conducting research and a corpus of empirical research (Smith, 2004: 40). Using Interpretive Phenomenological Analysis (IPA) is to first 'give voice' to respondents' concerns (describing) and to second 'make sense' (interpretive) of these concerns (Larkin, Watts and Clifton, 2006: 102).

This study centres around the lived experience of dementia and as a result one of the reasons a phenomenology based approach was deemed suitable was because data analysis within this method of enquiry follows a reductionist approach, where all possible meanings of statements and themes are investigated, resulting in a general description of the experience or the 'essence' of the experience (Creswell, 1998: 65). Applying this to my thesis, the 'essence' of the investigation is the lived experience. It argues that there is an objective world but it is experienced through consciousnesss, not through the senses (Sarantakos, 2005: 44). It views the world as being created by people, and as such it focuses on 'peeling back' the

layers and thereby getting to the essence of the person's perception of reality, where the person's reality (e.g. their experiences, attitudes, feelings and thoughts) is "treated as pure 'phenomena' and the only absolute data from where to begin" (Groenewald, 2004: 4). The reality in which people living with dementia exist may be very different to how other people perceive it.

1.5 Policy Context

Ireland has a mixed welfare economy where four sectors are involved in the provision of welfare, namely the public sector, the private sector, the voluntary sector (non-profit) and an informal sector (Fanning, 2006: 10). In Ireland, primary healthcare is means-tested and free of charge to those with lower economic means. Until 2008 primary health care was free to all people over 70 years, through the medical card system (i.e. the entitlement was universal for this age group). Means-testing has now been introduced, although the income thresholds are much higher for those over 70 years compared to the rest of the population, making the bulk of the population in this age group eligible for free hospital and GP care and free presriptive drugs including anti-dementia medication. Hospital care is not means-tested and is in principle available to all (although small, capped charges are levied for hospital stays). However, private health insurance is very common and a two-tier health system has come into existence: the publicly funded care system features rather nominal, capped charges (in the case of hospital care) or is free at point of access (in the case of primary health care services such as General Practitioner services) for those with a medical card; access to private services can be gained by those who have insurance or are able to pay (Tormey, 2003: 191). It is argued that the existence of this two-tier system reflects and exacerbates economic inequality. It is people with lower incomes who are reliant on public services. Private insurance and private services are more accessible for and more widely used by higher-income persons (Tussing and Wren, 2006: 101).

There are few dementia-specific policies in Ireland. In a sense this means that there is a 'clean canvas' for the development of appropriate and responsive health and social care for people living with dementia. The Years Ahead Report (Report of the Working Party on Services for the Elderly, 1988: 175) recommended that older people in general should be supported to remain living in their own homes for as long as possible. This is reiterated in the HeSSOP report (Garavan et al, 2001) which provided evidence of older people's wish to continue living at home. Recent policy reports have also re-echoed the importance of enabling people to remain living at home for as long as possible (Timonen, Doyle and Prendergast, 2006: 31-32). The majority of people living with dementia are over 65 years of age (O'Shea and O'Reilly, 1999: 43) and are therefore eligible to access and use older people's services both in the primary and secondary care systems. Medical care, excluding social care, for older people in the community has a legislative underpinning in Ireland (Mangan, 2006). For instance, people are entitled to a GP and a Public Health Nurse service but are not legally entitled to a home help[ii] or speech and language therapist. Dementia spans three specialised care continuums: older peoples' services, disability services and mental health services. When mental health services are accessed by people living with dementia it is generally Old-Age Psychiatric teams who intervene in the person's care. If dementia was viewed as a disability there would be clear pathways to care under disability legislation (The Disability Act, 2005); many people with early-onset dementia do access disability services. A difficulty with a system of general older people's care and specialised mental health and disability services is that many people living with dementia can fall between the cracks in these three care continuums.

In 1996, Keogh and Roche provided a model of possible pathways to access services for people living with dementia. They highlighted the provision of services in the home by a number of key providers

[ii] Home helps are provided by the Health Service Executive (HSE), usually to assist people with normal household tasks although they may also help with personal care. The main aim of this service is to facilitate the person's independent living at home.

(General Practitioners, Public Health Nurses (PHN), home helps, social workers, occupational therapists, physiotherapists, speech and language therapists and workers from the voluntary sector). Services provided in the community included: day centres, day respite, residential respite and assessment. Referrals to secondary care from the community were either to psychiatric services or age-related hospital services, where a range of services were offered. However, other than services offered by the Alzheimer's Society of Ireland (ASI), no dementia-specific services existed separately or within generic older person's care then, and now ten years later, little has changed. Where assessment of need is carried out, it is generally done by GPs or PHNs and there are no standardised assessment tools in use. The provision of services tends to be based on physical function alone rather than a more holistic assessment that would take into account quality of life and social aspects as well as medical need.

The 'Action Plan for Dementia', published in 1999, is still the main policy document addressing dementia-related social and health care issues in Ireland. It contains a list of 33 recommendations, the majority of which have not been implemented despite the general acceptance of these recommendations and indeed a commitment to their implementation in the Department of Health and Children's 2001 Health Strategy 'Quality and Fairness: A health system for you'. References to dementia are common in more recent policy reports such as the National Economic and Social Forum's Care for the Aged Report (2006). Dementia as a separate concern has received little policy focus: where policy about dementia does exist it is mostly embedded in larger generic policies and statements on ageing (NESF, 2006: 88).

1.6 Placing Myself in Context

I decided to undertake this study for a number of reasons. While working on a longitudinal European project (ENABLE) from 2001 to 2004, which involved people living with dementia as research participants I started to think about what it must be like to have

dementia. ENABLE was the first research project I worked on other than projects carried out during my undergraduate studies in sociology and my postgraduate studies in social research. One man in particular who was a participant in ENABLE, I will call him John, spoke to me in great detail about his experience of receiving a diagnosis of dementia and the subsequent process he went through to eventually accepting his changed situation. He told me what it felt like to see his boots at the back door and not know why he had left them there. Or walk upstairs or through his front door and become disorientated. It dawned on me that these experiences are sometimes felt by all of us, moments of disorientation, albeit not to the same extent as John's experience. However, it made me think of the potential to further understand the lived experience of dementia. Two years following his diagnosis John began to adapt to his diagnosis. He went back to his local haunts, began going out socially with his adult daughter. John's experiences showed me how he made sense of the changes or symptoms of dementia he experienced. The relationship I built up with John and other respondents through ENABLE inspired this investigation as they all had stories and experiences that I felt had not yet been told. I wanted to understand what the experience was like for them and investigate the lived experience in greater detail.

Like many people I had a close relative who had dementia. This is one of the reasons I initially became interested in dementia care and research. However, she passed away when I was quite young and my insight at the time into her dementia was limited. I do not have any personal experience of disability. Within my peer and kin groups there are only a small number who have disabilities of different sorts and to varying degrees. My personal experience of disability and cognitive disability in particular is limited. I relied on the people living with dementia who I have interviewed through different social research projects to inform me on what the experience is like.

1.7 Thesis Content

Chapter Two, 'Understanding Dementia', examines how common understandings of dementia have evolved. It addresses the question 'what is dementia?' tracing its conceptual development over time. This chapter investigates both traditional symptomatic-based and psychosocially based categorisations of dementia. It also explains why people with early-stage dementia were selected as a central focus of this thesis and concludes with an examination of current dementia-specific psychosocial interventions.

Chapter Three outlines modern approaches to and understandings of dementia, focusing on personhood, relationship-centred, social constructionist and social disability models of dementia and citizenship. It examines the existing literature on the lived experience, providing a context for the findings and discussion chapters. This discussion serves to illustrate how original research and thinking has progressed our understanding of the lived experience of dementia. Central themes relevant to this thesis identified in the literature chapter include: awareness, selfhood and the effect of others on the lived experience (including labelling and stigma), coping and management of the illness. Chapter Three concludes with a discussion of Irish health and social care policy and our system of service delivery, placing it in the context of different systems in other countries.

Chapter Four outlines the six research questions and outlines the methods used in this thesis. It details ethical considerations, data collection procedures and the analytical approach taken. Qualitative semi-structured interviews with people living with early-stage dementia, interviews with care-partners and interviews with policy experts were the main methods used. Ethical issues are examined extensively in this chapter, including considerations relating to the conduct of sensitive research, consent, capacity, the role of the researcher and reflexivity. The second part of this chapter presents detailed information on sample recruitment and data

collection procedures. The chapter outlines procedural steps within the IPA approach used to analysis the data. The chapter also contains reflections on how my background and personal characteristics affected each stage of the research process. The final part of this chapter considers the limitations of the methods used.

Chapter Five is the first of three findings and discussion chapters. It reports on the lived experience of dementia and examines findings on what this meant for respondents. It reports on the central themes that emerged from the analysis, namely awareness of dementia, responses to the onset of the illness (emotional and psychological) and coping with the illness.

Chapter Six examines how respondents with dementia engaged in their social worlds. It looks at respondents' social networks and the social contacts they had before and after the onset of the illness. This chapter also examines respondents' participation in social activities and how this involvement changed over time.

Chapter Seven presents the analysis of respondents' experiences within the Irish health and social care system. It examines referral processes and the pathways through which respondents were referred to different services. This chapter also looks at diagnostic and disclosure practices and examines the debate on what is perceived as best practice internationally.

Chapter Eight examines the policy implications of the three preceding findings chapters. It also draws on data collected from interviews with the six policy experts who were key informants for this thesis. In this way the chapter addresses some of the key policy issues and priorities in dementia health and social care in Ireland.

Chapter Nine summarises and further synthesises the key findings, relating these back to the research questions and the conceptual and theoretical framework of the thesis. I offer some concluding reflections on the processes involved in completing the thesis in this

chapter. This chapter also highlights what is original about the study and expands on the specific themes from findings which warrant further investigation.

CHAPTER TWO: UNDERSTANDING DEMENTIA

2.1 Introduction

Examining how dementia is understood and how these understandings have evolved over time requires an examination of changes in the conceptualisation of dementia. This chapter, therefore, investigates the shift from viewing dementia as senility or as a normal part of the ageing process to the 'Alzheimerization' or the medicalisation of dementia. How we understand dementia sheds light on the types of interventions that are available to people with dementia, whether they are predominantly medical and health-related or whether there have a social aspect. The chapter also explains why this thesis is focusing on the early stages of Alzheimer's disease and Vascular dementia rather than on the the early stages of all dementias.

2.2 Conceptualisation of Dementia Over Time

Dementia is not a new phenomenon. Written records throughout history contain many references to memory loss and senility. As early as 330 BC, Aristotle linked a decline in mental power to advanced old age (Karenberg and Förstl, 2006: 6). Negative connotations of memory loss in older age are also not new. In the middle ages, with a rise in mysticism, the philosopher Bacon saw senility as a consequence of original sin (Boller and Forbes, 1998: 126). These negative undertones are further accentuated by the numerous 'synonyms' used for dementia throughout the ages. Boller and Forbes (1998: 126) list these synonyms as alienation, amentia, anoea (extinction of the imagination and judgment), dotage, fatuitas (silliness), foolishness, idiocy, imbecility, insanity, lethargy, morosis, organic brain syndrome, senile dementia, senile psychosis, senility, simplicity and stupidity. This list shows us that dementia has strong

links to what is viewed traditionally as mental illness and many of these terms (e.g. stupidity and simplicity) are derogatory.

The term dementia was first used in 1797 by Dr. Phillippe Pinel (1745 – 1826). A debate, however, still exists on whether or not he coined the original expression. Some argue that it was first used in France as early as 1381 (Boller and Forbes, 1998: 126). Since Pinel used the term, medical science has advanced our knowledge of the biological causes of dementia. Indeed, Esquirol in the early 19th century listed some of the common 'causes' of the illness as menstrual disorder, head injuries, progression of age, ataxic fever, haemorrhoids surgery, mania and monomania, paralysis, syphilis, mercury abuse, dietary excess, wine abuse, unhappy love, fears, political upheavals, unfulfilled ambition, poverty and domestic problems (Boller and Forbes, 1998: 126). In some cases Esquirol showed great insight into the causes of dementia despite little empirical evidence.

Since this time there have been major advancements by the medical profession in understanding the causes of dementia, with lists of disorders of the dementia type based on differing etiology, namely Dementia of the Alzheimer's type, Vascular dementia, Dementia due to HIV, Dementia due to head trauma, Dementia due to Parkinson's disease, Dementia due to Huntington's disease, Dementia due to Pick's disease, Dementia due to Creutzfeldt-Jakob disease, substance-induced persistent Dementia and Dementia due to other multiple etiologies.

By far the most common form of dementia is Alzheimer's disease[iii], named after a German physician Dr. Alois Alzheimer who first reported the disease in 1906 (Cheston and Bender, 2003: 22). He identified plaques and fibrils in the brain of one of his patients, a woman called Frau Auguste D, as the cause of her disturbed and disorientated behaviour. However, until the 1970s, little or no research

[iii] Alzheimer's disease is characterized by the presence of (i) neuritic plaques which are layers of protein in between nerve cells and (ii) neurofibrillary tangles, areas of damaged nerve fibres which have become tangled (Burns, Page and Winter, 200: 11).

into Alzheimer's disease was undertaken. Premature senility was considered an illness, while senility in old age was seen as a normal part of the ageing process (Lyman, 1989: 597). Alzheimer's disease finally became a policy issue 70 years after Alois Alzheimer highlighted the first documented case. Cheston and Bender (2003) identified the following reasons for this renewed focus on the illness: (i) an increase in life expectancy, (ii) fear and panic around these demographic changes, (iii) the fact that up until this time there had been no conclusive evidence that dementia was not a normal part of the ageing process[iv] and (iv) the work of an American Neurologist, Dr. Robert Katzman. Katzman broadened the conceptual boundaries of Alzheimer's disease and in 1976 he recast it as the fourth or fifth most common cause of death in the United States (Fox, 1989: 60).

The increased attention on Alzheimer's disease has created what is known as the 'Alzheimerization' of dementia. This refers to the common use of the term Alzheimer's disease for all dementias. The cause of Alzheimer's disease is still not fully understood. However, the presence of Alzheimer's disease is characterised by plaques and tangles, which is the build-up of protein in the brain. Viewing dementia as a disease considers the body as a machine, one that can be repaired when it breaks down (Bond, 2001: 45). The Alzheimerisation of dementia was an easier way for people to comprehend the disease and as such it created an element of hope of a cure.

Although there have been advances in medical treatments (e.g. cholinesterase inhibitors) to help slow down the progression of dementia a cure is still a long way off. As a result, there is often the misconception that no successful interventions exist and dementia can instigate feelings of fear and dread. Indeed the contemporary perceptions of dementia are still very negative. In modern times the term dementia has conjured up images of 'a living hell' (Goldsmith, 2002: 20) or a 'social death' (Kitwood, 1997a: 137). A prevalent social

[iv] This relates to the emergence of the identical nature of the clinical and pathological manifestations of pre-senile and senile dementia (Boller and Forbes, 1998: 130).

myth surrounding memory is that old age is a period of inevitable decline in memory. Job (1992: 243) outlines another common myth: "inevitably in those living to be old, there comes a time when there is no space left for recent information and in attempting to pack more in, old memories spill to the surface and people are reduced to living in the past". These social myths contribute to ageism in practice, whereby older people are seen as unable to learn new things and as being out of touch with reality. However, there has been a growing awareness of Alzheimer's as the 'disease of the century' and on refuting "the myth that senility is an inevitable condition of old age" (Lyman, 1989: 597). With this in mind, this thesis is set out to tackle and dismantle some of the myths by exploring the reality of the experience for people living with dementia.

2.3 What is Dementia?

The following section outlines medical classifications of dementia and shows how the medical model came to dominate treatment and care interventions. It is common for interventions, whether medical or psychosocial, to be offered to a person within a medical environment. It is often the case that one must receive a medical assessment before referral to other treatments/interventions. The conceptual framework and a discussion of psychosocial (personhood, disability models etc.) approaches to understanding dementia are presented in Chapter Three.

A debate exists on whether dementia is a normal part of ageing or whether it is a disease process (Woods, 2005: 252). As the prevalence of dementia increases with age people tend to attribute it to ageing. On the other hand, some people below the age of 60 and 50 years can develop a dementia and the biomedical research community argue that there is a clear distinction between dementia which reflects one or more specific disease processes and normal ageing (Woods, 2005: 252). However, as Woods (2005: 252) states, brain changes do not always concur with the clinical presentation as studies examining the brains of people aged over 75 years show that

the physical manifestation of dementia is less straightforward than the simple disease paradigm suggests. This weakens the application of the disease model, particularly in later life, "as multiple pathologies are more common than single disease processes" (Woods, 2005: 257).

Outside of this debate, dementia is generally associated with older age as there are significantly higher numbers of people with dementia over 65 years and the percentage of people to develop a dementia increases with age. Dementia is not a disease or illness[v] in itself. Rather it is a broad term used to describe a group of illnesses that cause memory, cognitive and sometimes social and behavioural decline. Dementia occurs when there is a serious deterioration in a person's intellectual and emotional state (Burns, Page and Winter, 2001: 2). Burns, Page and Winter (2001: 3) characterise it by loss of memory, loss of higher brain function, presence of psychiatric symptoms, behavioural disturbances and changes in the ability to perform activities of daily living. It can affect mood and behaviour, sometimes causing the person to display uncharacteristic personality traits. The Alzheimer's Society of Ireland list ten of the early signs of dementia as: memory loss, difficulty in performing everyday tasks, changes in mood and behaviour, changes in personality, disorientation in familiar surroundings, problems with language, poor or decreased judgment, misplacing things regularly, difficulty in solving problems or doing puzzles and loss of interest in starting projects or doing things (Alzheimer's Society of Ireland, 2003: 4). It is because of the various combinations of symptoms experienced by individuals that there is no one solution to the provision of care (O'Shea and O'Reilly, 1999: 33).

The lack of social policy relating to dementia (see Chapter Three for a further discussion on this) and the unpinning of medical care and

[v] For the purposes of this thesis, as it is a psychosocial investigation, dementia is viewed as an illness, where illness refers to "how the sick person and members of the family or wider social network perceive, live with and respond to symptoms and disability" (Kleinman, 1988: 49, as cited by Nettleton, 2006: 81). This distinguishes illness from disease, where disease refers to a biological or physical occurrence; this is the primary concern of medical practitioners (Nettleton, 2006: 81).

not social care in legislation, suggests that in Ireland, the medical model remains the dominant influence guiding dementia policy, services and practice development. Therefore this thesis, while taking a psychosocial approach, cannot ignore medical aspects of and approaches to dementia. A difficulty with the medical model is that it is reductionist i.e. it views illness and disability as a problem caused by the disease and/or trauma. While it is important to understand dementia-related biological changes and the physiological effects of dementia, distinctions need to be made between the biological symptomatic effects of the illness and the psychosocially based responses to the illness.

The universally accepted American Psychiatric Association (2000: 148) definition of dementia describes the diagnostic features of dementia as multiple cognitive deficits that include "memory impairment and at least one of the following cognitive disturbances: aphasia[vi], apraxia[vii], agnosia[viii], or a disturbance in executive functioning. These cognitive deficits, which determine the presence of dementia, must be sufficiently severe to cause impairment in occupational or social functioning and must represent a decline from a previously higher level of functioning" (American Psychiatric Association, 2000: 148).

2.4 Why Focus on Alzheimer's disease and Vascular dementia?

An inclusion criterion for the study was that respondents had to have either Alzheimer's disease and/or Vascular dementia. A number of reasons were identified for this. First, Alzheimer's disease is the most prevalent form of dementia, with approximately 60% of dementias being of this type (Burns, Page and Winter, 2001: 3). Since recruitment for this study was expected to be challenging: it was therefore

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[vi] Aphasia is impairment in the understanding or transmission of ideas by language in any form - reading, writing, or speaking - that is due to injury or disease of the brain centres involved in language (American Psychiatric Association, 2000: 820).

[vii] Apraxia is: "Impaired ability to carry out certain purposeful muscular movement" (Collins Shorter English Dictionary, 1993: 51).

[viii] Agnosia is the partial or total inability to recognize objects by use of the senses (Random House, 2006: Dictionary.com Unabridge, v 1.1).

inconceivable that the largest group of people living with dementia would not be included in the sample. Although it is difficult to give a definite diagnosis of Alzheimer's disease as this is not possible without an autopsy, by ruling out the other commonly known dementias, practitioners can then rule-in the likelihood of Alzheimer's disease. As might be expected, the largest group in this study's sample had Alzheimer's disease (N=12). The onset of Alzheimer's disease is also gradual and constitutes continuous memory and cognitive decline. Therefore, people with Alzheimer's disease tend to have slower progression into the illness.

People with the second most common form of dementia, Vascular dementia, were also identified as suitable for study inclusion. Vascular dementia accounts for approximately 20% of all dementias (Burns, Page and Winter, 2001: 3). This dementia occurs when there is a hardening of blood vessels in the brain. As a result, it becomes increasing difficult for adequate blood supply to reach brain cells and these cells become damaged and/or die. The onset of Vascular dementia is usually more sudden than Alzheimer's disease and is followed by a fluctuating course characterized by rapid changes in functioning rather than slow progression (American Psychiatric Association, 2000: 160). People with Vascular dementia were included in this study because they have fewer personality changes compared to people with other dementias. Vascular dementia is also easier to diagnose (a diagnosis of dementia was a prerequisite for inclusion) and it is quite common for people to have mixed Alzheimer's disease and Vascular dementia. In four cases, respondents recruited for this thesis had mixed Alzheimer's disease and Vascular dementia and in one case a respondent had a diagnosis of Vascular dementia.

The reason why other forms of dementia like Lewy Body dementia, Picks disease, Creutzfeldt-Jacob disease, Parkinson's disease and Huntington's chorea, Frontal-lobe dementias, alcohol and Aids-related dementias, were not included is that they are characterised by greater changes in the person's character and it was felt that

such changes might make interviewing more difficult. Furthermore, a person can deteriorate more rapidly when they have one of these dementias. These types of dementia are also not as frequently diagnosed as Alzheimer's disease or Vascular dementia.

My previous research experience where people living with dementia were included in the research process also directed this decision. I knew how difficult it can be to recruit people living with early dementia, as early diagnosis is not common, often people are not told a diagnosis and recruitment for medical/clinical research is prioritised over psychosocial research. Therefore, I wanted to simplify the recruitment process and create a stricter inclusion criteria for possible participants (see Chapter Four, section 4.6.4 for a further discussion on inclusion criteria).

2.5 What is Early-Stage Dementia?

As mentioned above, the symptoms of dementia include memory loss and the gradual deterioration of memory and cognitive ability. These symptoms can be crudely categorised into a number of different developmental stages. These are differentiated by different behavioural patterns and levels of cognitive ability. O'Shea and O'Reilly (1999: 32-37) outline these as: the first or early-stage of dementia which includes the symptoms of forgetfulness, reduced attention span, lack of spontaneity, lack of initiative, disorientation of time and place, depression and fear and anxiety or suspiciousness about possessions or about the behaviour of others. The second stage occurs when there is an emergence of significant difficulties, characterised by problems recognising close family and friends, difficulties dealing with money, restlessness and agitation especially at night, repetitiveness in conversation and actions and increased disorientation and forgetfulness. The third stage, where diagnosis is often made, is differentiated by uncharacteristic mood swings and outbursts, speech impairment, wandering around the home and away from home, impaired judgment and increased disorientation of time and space. O'Shea and O'Reilly state that the fourth stage is

when dependency and incapacity occur. Assistance is required in all activities of daily living. The person may no longer talk, they may no longer recognise family members, they may be unable to make decisions and they may have developed additional medical and physical conditions. O'Shea and O'Reilly state that the final or end stage occurs when the person no longer communicates or responds.

Dementia is more commonly differentiated into three stages, categorised by the Alzheimer's Society of Ireland (2003: 7-9) as 'Mild' (repetition, loss of interest, difficulty in remembering names for common items, mislaying things, personality changes and difficulty in grasping complex ideas), 'Moderate' (place disorientation, increased confusion, difficulty performing tasks of daily living, being argumentative, restlessness and agitation, wandering and difficulty sleeping) and 'Severe' (communication difficulties, not recognising family members, inability to care for oneself and increased mobility difficulties). Although the O'Shea and O'Reilly and ASI classifications are crude and are not applicable to all people living with dementia, they illustrate the types of symptoms associated with dementia. Whilst some would argue that the staging of dementia is not that useful, and no two people living with dementia will have similar experiences, it at least provides some benchmarks about what people living with dementia are likely to confront.

Keady and Nolan (1994: 665-667) take a different and for the purposes of this thesis as more insightful approach to categorising the development of dementia. They outline dementia in nine psychosocial stages. This places the experience of dementia into a broad context that is affected by emotional, psychological, social and environmental factors, as well as biological changes. The following is an outline of their categorisations:

Slipping: small 'slips' in memory become apparent to the individual. When these slips become more frequent they can no longer be ignored and coping behaviours are put in place.

Suspecting: the above slips become so frequent that they can no longer be ignored or discounted and the individual begins to suspect that something is wrong.

Covering up: the individual begins to actively hide the difficulties they are experiencing. However, as the illness progresses it becomes increasingly more difficult to cover these up from family and friends.

Revealing: the individual reveals the difficulties they have been experiencing to other family members. However, this revelation may still be retained within the family and formal diagnosis or confirmation may be delayed.

Confirming: a formal diagnosis is sought and given. The open acknowledgement of the problem is made.

Maximising: adaptive techniques are implemented to assist the individual in coping with their diagnosis.

Disorganisation: awareness of actions and decision-making abilities becomes lost.

Decline: relationships that were once normal become uncertain and the individual becomes increasingly dependent on others. Admission to long-term care may follow.

Death: the final or 'ultimate' phase is death.

Keady and Nolan's categorisation gives a helpful framework in which respondents' experiences can be placed (see Chapter Five for full details). Their categorisation is extremely useful when we try to interpret and understand what the experience of dementia is like for someone.

This thesis focuses on people living with the early stages of dementia. The two main reasons for recruiting a sample of people with mild to moderate dementia were that they were more likely to live in the community and also more likely to be able to give informed meaningful written consent: these were two prerequisites for inclusion in the study.

2.6 Dementia Treatments and Interventions

With shifts in thinking ranging from the medical model, personhood, the social disability model and sociological approaches, changes in treatments and interventions in dementia care have also occurred. A number of non-pharmacological interventions and treatments are available with a new focus on the rehabilitation of people living with dementia (Mountan: 2005).

Spector (2006: 381) argues that there is a dominance of pharmacological interventions as the main treatment offered to people living with dementia. Large-scale clinical (control) trials are often viewed as the gold standard for evidence-based practice. This is in contrast to non-pharmacological interventions, which are often evaluated on a much smaller scale in studies that sometimes suffer from methodological weaknesses (Woods and Orrell, 1996). It can be argued that the heavy medical focus of current treatments in dementia care is because randomized control trials are used to measure the effectiveness of drug therapy interventions and are often followed by funding for the implementation of these therapies. Many interventions (psychosocial) which hold great promise are not tested rigorously enough to provide an evidence base for a widespread adoption of the intervention (Mittleman, 2008: 1).

2.6.1 Pharmacological and non-pharmacological treatments

In terms of medical interventions, cholinesterase inhibitors are a common drug treatment for dementia. They are sometimes referred to as anti-dementia medications. There is evidence that these drugs provide modest benefits, however some argue that they do not live up to expectations. Their legacy may not be in the direct treatment effect on a person's Alzheimer's disease but the level in which they have helped to raise awareness and recognition of dementia (Rodda and Walker, 2009: 437).

In some cases these medications (widely known and used brands include Aricept, Exelon and Reminyl) can improve or stabilise

cognitive function and as a result users of these drugs can experience a period where they plateau. As stated already evidence suggests that their benefits are modest. In some cases there are adverse side effects such as vomiting, nausea, loss of appetite and diarrhoea. For those who are in the middle stages of dementia, the most common recommended medication is Memantine. It is effective in improving cognition and daily functioning (Miller, 2004: 57). Adverse side effects of this drug include dizziness, diarrhoea, headache, falls, hallucinations, agitation, urinary incontinence and insomnia. Natural treatments for dementia include vitamin E, gingko bilboa, beta-carotene, selenium and magnesium (Miller, 2004: 57).

The National Institute for Health and Clinical Excellence (NICE) in the UK (2006: 30) concluded that drug treatments (Aricept, Exelon and Reminyl) for Alzheimer's disease were limited and they should be used as an option in the management of Alzheimer's disease of 'moderate severity only'. As a result of this finding, common drug treatments for dementia are no longer available free of charge for those in the early stages of dementia through the National Health Service in the UK. However, in Ireland there are no such restrictions and once someone has been prescribed these medicines (and either has a medical card or is prepared to pay the costs themselves) they can avail of them.

Dementia drugs are tested with the help of randomised control trials (RCT), a research method that is often viewed as the 'gold standard'. As Spector (2006: 381) points out, 'endorsement' of a drug treatment by a successful RCT is often required before funding is given for their widespread use. There is some debate about the types of research methods used to assess the efficacy of cholinesterase inhibitors (Journal, International Psychogeriatrics, 2008: 20(2)). In this Journal, Kaduszkiewicz et al (2008: 278-279) state that randomised control trials (RTC's) do not provide convincing evidence of the efficacy of cholinesterase inhibitors due to methodological shortcomings. These shortcomings are also valued differently by different reviewers of the

evidence. These authors state that neither pharmaceutical companies (who often fund such trials) nor other authors have performed comprehensive sensitivity analysis in order to substantiate the results of RTCs. These authors also state that there is no evidence from RTCs that cholinesterase inhibitors delay entry into long-term care or improve quality of life, as well as having significant side effects. RTCs which have broad exclusion criteria and short trial duration result in external validity being low. Due to these reasons they conclude that better methods of quality assessment of clinical trials are needed and trial data from the pharmaceutical industry should be available and accessible for research purposes. Birks (2008: 285) counters these arguments by stating that no trials are perfect and there is a need to work within their limitations. She states that evidence suggests that the size of bias is not too large that it eliminates treatment effect. The debate on RTC's raises the question of how effective are they as the 'gold standard' in evaluating treatment interventions for dementia?

2.6.2 Rehabilitation

Despite the increasing emphasis on quality of life issues for people living with dementia, psychosocial and rehabilitative therapies are still not widely available to them (Spector, 2006: 381). It has already been stated that one of the reasons for this lies in the expectation that more evidence-based research is required to test interventions and therapies before they can become more commonly used.

Quality of life is a complex issue in dementia and is affected by a number of different variables. It can be influenced by psychosocial interventions such as music therapy, reality therapy, reminiscence[ix], cognitive stimulation therapy, self maintenance therapy, validation therapy (including life stories), use of external aids (e.g. assistive devices) and sonas (a system of multi-sensory stimulation involving music, touch, scent and simple memory exercises incorporating structure and repetition). Miller (2004: 57) lists some additional

[ix] Reminiscence therapy is the use of stimulating material (pictures, songs, newspaper etc.) to evoke memories (Brooker and Duce, 2000: 354).

therapies that include bright light therapy, aromatherapy, relaxation therapies and acupuncture. Successful psychosocial interventions need to take an individualized approach and adhere to Marshall's (1990: 7) contention that "intervention has to be based on an understanding of...the past experience, personality and present circumstances of the person with dementia".

Spector et al (1998) undertook a Cochrane systematic review of the use of reality orientation in dementia, and found significant benefits in both cognition and behaviour following the intervention. Iliffe and Drennan (2001: 63) highlight a number of psychosocial interventions that have proved successful:

- Mood management: this is working on negative and unhelpful beliefs (in the patient and those around them) to promote adaptation
- Cognitive rehabilitation: enhancing retained cognitive strengths and developing compensatory strategies to optimizing daily functioning[x]
- Memory training: improving the ability to recall simple information such as the names of friends or neighbours
- Life review: fostering integrity rather than despair, this is the basis for reminiscence therapy.

These interventions are important social supports that can offer people living with dementia some stimulation and further capacity for independence and assist them in managing day-to-day living. They constitute recent developments in dementia care, reflecting a new culture and a shift from the 'diseased brain' and biomedical focus.

To expand on themes raised in the early section Clare (2005a: 180) states that people living with dementia can maintain the ability to learn new associations and information, even after the onset of dementia, as they can adjust their behaviour and responses.

[x] In 2006 Spector presented the significant benefits found to cognition and quality of life of a multi-centred, radonmized controlled trial on cognitive stimulation therapy.

Rehabilitation is centred on assessment of function, psychosocial activities, psychotherapeutic modalities, sensory stimulation, interventions to improve functional ability and abilities to undertake activities of daily living, the use of assistive technologies and methods of self-management (Mountain, 2005). Rehabilitation programmes are happening across the globe, for example in Munich an Alzheimer's Therapy Centre provides a four week residential treatment programme for people living with dementia and their care-partners. This programme incorporates interdisciplinary and integrated rehabilitation concepts. It takes into account somatic, psychiatric, functional and psychosocial aspects of dementia (Romero and Wenz, 2001: 338). Allied health professionals such as Social Workers (Parsons, 2005), Occupational Therapist (Davidson, 2005), Speech and Language Therapist (Harris, 2005) and Community Psychiatric Nursing (Barlow, 2005) are also providing valuable rehabilitation to people living with dementia.

2.7 Chapter Summary

This chapter has looked at understandings of dementia throughout history, from early explanations through to more recent medical descriptions and psychosocial classifications. Changes in conceptions and understandings of dementia have occurred in tandem with an increase in the identification of the number of people experiencing dementia. This chapter has also explained that early-stage Alzheimer's disease and Vascular dementia were chosen as two of the inclusion criteria for the study because they are the two largest causes of dementia and are characterized by fewer personality and behavioral changes in comparison with other dementias.

The chapter has aruged that the significant advancements being made in our understandings of dementia are mirrored by advancements in pharmaceutical and psychosocial treatments for the illness, although there is huge scope for further development. However, the current culture of funding requires evidence-based

research before psychosocial interventions become commonly used as treatments for dementia. In terms of non-pharmacological interventions randomised control trials on Reality Therapy for persons with dementia are providing some evidence that they have a beneficial effect on the cognition and behaviour of people living with dementia (Spector et al, 2000). This could mark the beginning of the widespread provision of rehabilitative and psychosocial interventions to support the person with dementia. Despite some debate RTCs are still the predominant marker for evidence-based research which garners large-scale funding. This thesis provides insights into the experiences of people using available interventions and treatment. For professionals who are developing medical, psychosocial and/or rehabilitative interventions, this thesis offers the opportunity to understand the social context in which their treatments/interventions would be used.

CHAPTER THREE: Literature Review and Policy Context

3.1 Introduction

Chapter Two outlined how understandings of dementia have developed over time. This chapter expands on Chapter Two by outlining a range of models and approaches used to understand dementia, including the medical model, Personhood, relationship-centred approaches, social constructionism, the personal tragedy model, social disability models and the citizenship model. The changing nature of the conceptualization of dementia, as shown in Chapter Two, suggests that the currently dominant models should not be accepted automatically. As Schäfer (2005: 2026) states, "recognizing that change is constant reminds us of the provisional nature of our current knowledge". I feel that the experience of dementia cannot be conceptualised solely within one model, therefore the conceptual framework of this thesis applies elements of three approaches (Personhood, social constructionism and citizenship). These approaches and the ways in which I have drawn on them are explained and discussed in detail below. They also acted as a lens through which I viewed the raw data.

This thesis set out to improve our understanding of the lived experience of dementia and the policy and practice implications of the findings (in the Irish context). The central crux of this investigation is that by gaining an insight into the lived experience, the needs of people living with dementia can better be understood and thus more appropriately met. Therefore, to deepen our understanding of this central topic, it is important that an extensive review of the existing literature on the lived experience is undertaken and this constitutes the second section of the chapter. The literature reviewed in this chapter also helped to shape the research questions and acted as a guide to achieving best practice in the use of research methods.

As the lived experience of dementia in this study is examined within the broader context of the Irish health and social care system, this chapter concludes with a discussion of health and social care policy and service delivery in Ireland, with some comparisons drawn between the Irish system and systems elsewhere.

3.2 Modern Concepts of Dementia

Kümper et al (2005: 1200) state that during the 1990s, the traditional way of thinking about dementia and dementia care (medical models) came to be questioned. The 'therapeutic nihilism' associated with the medical model often shaped the professional and service approaches to dementia care and contributed to the public fear and stigma associated with dementia (Kümper et al, 2005: 1200). In recent years there has been a shift in how dementia is viewed. Hulko (2004: 240) talks about the conceptual shifts in viewing dementia as (a) both a brain disease and a normal part of the ageing process, and as (b) a psycho-neurological condition, to viewing it as (c) a disability, (d) a mental health problem and (e) a social construction. The following section considers some of the modern conceptual frameworks used to characterise and understand dementia, namely; Personhood, relationship-centred approaches, social constructionism, dementia as a disability and the citizenship model. It also presents the conceptual framework of the study by discussing the reasons why elements of the Personhood, social constructionism and citizenship approaches constitute the thread which ties together my interpretations of the data, the discussion and the conclusions.

3.2.1 Personhood

One of the most influential people to shift the focus from medical to psychosocial understandings of dementia was the British Clinical Psychologist, Tom Kitwood. In the 1990s he revolutionized how dementia was viewed with his theory of Personhood in dementia care. Kitwood's thinking shifted the focus from 'person with **dementia**' to '**person** with dementia'. This helped to create a new culture of

care based on a humanistic perspective[xi]. The term 'Person-centred' has its origins in the work of Carl Rogers and Client Centred Psychotherapy, where the client is the expert on themselves and the therapist is the facilitator in the person's search for self-actualization (Brooker, 2004: 215). Kitwood's application of person-centred care was the first time it was applied in the dementia care field (Brooker, 2004: 215). Kitwood's (1997a: 8) model defines Personhood as: "a standing or status that is bestowed upon one human-being by others, in the context of relationship and social being, it implies recognition, respect and trust". This definition was drawn from three main types of discourse as outlined by Kitwood in his 1997 work 'Dementia Reconsidered'; these were transcendence, ethics and social psychology. Discourse around transcendence sees the being-in-itself as sacred and life is revered. Principles of ethical discourse are that each person has absolute value and we must treat each other with respect. The origins of Personhood within social psychology are concerned with self-esteem and the place of the individual within a group and the continuity of a person's sense of self.

Kitwood outlined the components of dementia as equal to personality + biography + health + neuro-impairment + social psychology (Gilliard et al, 2005: 575), where its manifestation has many sources. This was one of the first times non-biological factors were considered in how dementia was regarded, experienced and treated. The innovation of Kitwood's position was that he considered psychosocial factors as contributing to the development of dementia (Adams, 1996: 949).

The promotion of Personhood has also changed how people living with dementia are spoken about. Bartlett and O'Connor (2007: 108) state that Personhood has done much to challenge the stigma and discrimination associated with dementia. As shown in Chapter Two, the way dementia is spoken about has improved. We also now incorporate the voice of people living with dementia in research and

[xi] Where a humanistic perspective focuses on the person's identity rather than on their illness (Beart, 2007: 571).

policy development in an attempt to understand the dementia experience. Through understanding the lived experience of dementia combined with successful rehabilitation and psychosocial interventions for people, hope is provided that positive change can occur (Bartlet and O'Connor, 2007: 109-110).

3.2.2 Relationship-centred approach

Person-centred care has become a watchword for good dementia care practice (Nolan et al, 2004: 45). However, there have been issues within person-centred care that have raised questions around the adequacy of its use for people living with dementia. It has been argued that however essential person-centred care is, this model, which provides a privileged place for the individual with dementia, is inadequate (Nolan et al, 2004: 46). These authors developed person-centred care into a relationship-centred approach, where the importance of interactions between people is seen as the foundation for any therapeutic activity (Nolan et al, 2004). People belong to networks of social relationships which are connected and interdependent (Nolan et al, 2004: 47) and these two factors need to be considered within any model of dementia care.

The quality of care people living with dementia receive is positively influenced by caregivers (formal and informal) who: (i) respect Personhood (ii) value inter-dependence and (iii) invest in care-giving as a choice (Nolan et al, 2004: 46). In terms of care provision, people with early-stage dementia have different needs than those in the later stages; indeed they may not have any traditionally viewed care requirements. However, a relationship-centred approach recognises that there are other stakeholders involved in the dementia experience, others who are dealing with a diagnosis e.g. spouses and children who also need support. It is important to note that formal service providers are also valued stakeholders and that they too can influence the lived experience for the person with dementia. Their needs should not be discounted. A relationship centred approach was acknowledged in the data collection methods used in this thesis

where both the individual's and his or her care-partner's views were investigated.

3.2.3 The socially constructed nature of dementia

Social constructionism, with its roots in sociology and psychology, is concerned with how we make our worlds and how in turn we are made by our worlds (Harding and Palfry, 1997). Like Kitwood, social constructionists move beyond the medical model of dementia. They argue that dementia arises as a result of a sociological or psychological process rather than solely as a result of the physical deterioration depicted in the medical model (Harding and Palfry, 1997). They also question the unequal knowledge base between the medical professional and the person who has dementia. This unequal base excludes the person from any discourse around the provision of their care (Innes, 2002: 485). The person with dementia is at a disadvantage due to a lack of power and knowledge.

Another central tenet of social contructionism is that people construct their realities in the process of interaction with other people (Palfry and Harding, 1997: 12). Social constructionism contends that the world is subjective, understood through investigating meaning and interpretation. 'Facts' are created by social interactions and in how these facts are interpreted (Nettleton, 2006: 17). How a person's social world is understood can be garnered through examining their lived experience or the individual's meaning of their world, where individuals actively create and/or construct their social world (Harding and Palfry, 1997). This theoretical approach was instrumental in the decision to include people living with dementia as the main research participants in this study. The reality in which the person lives is of central importance to understanding the experience.

3.2.4 Moving beyond the personal tragedy model

More recently and particularly since the work of Kitwood in the 1990s, dementia has been re-conceptualised as a disability. The Disability Act of Ireland (2005) states that: "Disability, in relation to a person,

means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment" (Department of Justice, Equality and Law Reform, 2005: 6). This definition focuses on restrictions in capacity and participation. Previous discourses around disability focused on impairment and function where: "Impairment is the functional limitations within the individual caused by physical, mental or sensory impairment; disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others because of physical and social issues" (Oliver, 1998: 1447). People living with dementia experience memory and cognitive impairment, but they are also unable or disabled from taking part on an equal level in society and therefore the experience becomes one of cognitive disability.

In the last century disability amounted to a personal tragedy, it was a social problem, a 'burden' on the rest of society, equated with flawed minds and bodies (Barnes and Mercer, 2003: 1). Like the medicalisation of dementia, the **medical or 'personal tragedy' model** prevailed in any examination of disability (Drake, 1999: 10) and solely focused on the workings of the body. This model placed the disabled person in the role of victim and individuals were defined in terms of their functional limitations. The individual with dementia was considered within a sickness framework (Gilliard et al, 2005: 572). This model can be critiqued, as it fails to see the non-medical disadvantages experienced by those with a disability. Others have also viewed the model as equating disability with abnormality (Drake, 1999: 10). Until the late 1980s and early 1990s dementia followed a similar course with the dominance of the medical model, which established dementia as a disease category "set by a trajectory of linear decline" (McColgan, 2004: 172).

The **social model of disability** moves past the personal limitations that impair people to the social restrictions imposed on them. This social model views disability as "a complex collection of conditions, many

of which are created by the social environment. Hence the management of the problem requires social action and it is the collective responsibility of society at large to make the environmental modifications necessary for the full participation of people with disabilities in all areas of social life" (World Health Organisation, 2006: 20). Access does not solely refer to physical access but also refers to active inclusion and participation in society.

3.3 Social Models of Disability

The theoretical framework of this thesis incorporates Kitwood's concept of Personhood and follows the principles of social constructionism. It also adapts the social model of disability, broadly applying it to how dementia is viewed. The Social Model of Disability was conceived over 20 years ago by the Union of the Physically Impaired Against Segregation (UPIAS) under their Fundamental Principles of Disability (Tregaskis, 2002: 457). The UPIAS challenged the idea of the 'able-bodied' society where normalcy was a prerequisite for participation. Social disability models clearly distinguish between physical impairment, functional limitations and disability, where physical impairment is a personal characteristic and functional limitation refers to an individual's performance of an activity or task without reference to a situational context, while disability is a situational variable (Putnam, 2002: 804). The social disability model views disability as a political and social issue, rather than a medical one (Oliver, 1998: 1446). Putnam (2002: 802) states that disability is "not inherently a part of the person, but rather a function of the interaction between the person and the environment"; therefore disability is the dependent variable.

There are many derivatives of the social model of disability, drawing on philosophical and sociological approaches including Marxist materialism, cultural politics, feminism, ethnicity research and psychoanalysis (Tregaskis, 2002: 466). However, many of these offshoots of the social disability model focus on physical disability rather than intellectual or cognitive disability. Marshall (2005: 17)

characterises the social disability model of dementia where the experience of dementia depends on (i) the person (e.g. personality, their history), (ii) all the factors in their environment (e.g. light, heat, physical surrounding), (iii) their health (medication, impairment, illness) and (iv) their background (e.g. family, friends, neighbours).

Applying the social disability model to how dementia is understood does not negate the fact that someone with dementia may also require physical care, particularly as the illness progresses. However, the focus is also put on what the person can still do, on their abilities. Despite widespread knowledge of the disability model, the medical model still dominates how people are treated and cared for. In the last 40 years there has been a move away from the traditional approach of institutional care with new thinking on the promotion of independence. This has been the case for intellectual disability and for old-age services. Can we say the same for those living with dementia? One of the aims of this thesis is to investigate this.

3.4 Citizenship Model

So far this chapter has presented a range of approaches and theoretical perspectives. All of these approaches lend themselves to understanding dementia, how it is experienced and how it is viewed in larger society. In many cases one approach is helpful for understanding the application of another model/theory, for example the social disability model lends itself to understanding the application of the citizenship model to dementia.

The citizenship model of dementia offers a framework in which people living with dementia can be empowered (Baldwin, 2008: 222). The concept of citizenship goes back as far as the Roman Empire, however modern concepts of citizenship date back to the French revolution (mid 19thcentury) where it was linked to equality (Bartlett and O'Connor, 2007: 111). This model links the personal with the political (Baldwin, 2008: 222). The citizenship model asserts that: (i) people living with dementia can and have a lot to contribute to

society, (ii) people living with dementia have rights and responsibilities and (iii) people living with dementia are the experts (Marshall, 2007). The citizenship model promotes the status of the person with power and entitlement to the same from life as everyone else (Bartlett and O'Connor, 2007). While Personhood is concerned with individual matters (the person at an individual level), citizenship conceptualizes dementia within political and societal structures and frames the personal experience within this (the position of the self in a collective) (Bartlett and O'Connor, 2007). In this way it challenges discrimination.

If citizenship is concerned with people living with dementia being legitimate members of society, then the condition of not being a member is associated with exclusion from those rights and indeed those obligations that are associated with membership (Barnes, Auburn and Lea, 2004: 188). Bartlett and O'Connor (2007: 111) argue that citizenship as a lens through which to view dementia has the potential to improve the status and treatment of those who are disempowered. It challenges their marginalisation from mainstream society due to disability and denial of full citizenship.

3.5 Conceptual Framework

A quote from Schäfer (2005: 2026) is included in the introduction to this chapter, where we are reminded to recognise that change is constant. For instance, for a long time dementia was viewed solely through the medical model, where the person was the biological condition; they had no control, power or agency. They were sufferers, often seen as unaware. Other evolving theories and approaches have been presented in the above section. They show us how understandings of dementia have changed and are changing. In relation to this thesis, I wanted to place the person living with dementia at the centre of the research enquiry, but I also wanted to place their lived experience within a broader socio-political context, which in turn called for understanding (health, care and other) policies as they pertain to people living with dementia. The approaches that helped to shape and guide this thesis by

constituting the initial conceptual and theoretical framework are the Personhood, citizenship and social constructionist approaches.

Personhood helps us to understand the subjective or lived experience of dementia as it considers and acknowledges that other people's treatment and interaction largely affects the experience (see section 3.4 above). Kitwood differentiated between impairment and disability, where impairment was a result of neurological changes, while disability was a result of restrictions on activity by contemporary social organisation (Baldwin, 2008: 223). Personhood is important in an examination of dementia as through its introduction into dementia literature, research and practice we have moved from "failing to even consider whether persons with dementia have anything to say, to acknowledging that indeed they do and recognising the importance of hearing their perspectives" (Bartlett and O'Connor, 2007: 109).

Personhood helps us understand the individual. However, as Baldwin (2006: 223) states, it is an apolitical concept. It is important but it does not view the person with dementia as someone with agency; as someone that can exert power and influence (Bartlett and O'Connor, 2007: 110). The citizenship model in turn focuses on power, agency and inclusion. Bartlett and O'Connor (2007:107) argue that as lenses through which to view dementia, both Personhood and citizenship are too narrow. Personhood is essentially apolitical and citizenship presumes a person's self-cognisance to exercise their rights and responsibilities. Therefore, these authors argue if the field of dementia research is to progress a wider lens is needed, one which is inclusive of both Personhood and citizenship but also recognises the complexities of human experience. In relation to this thesis I attempted to understand the lived experience of dementia (thus taking a person-centred approach) but also to place this experience within a macro framework (in this case the social and health care system in Ireland which has its own unique policy context); I therefore wished to gain an understanding of the experiences of the respondents as (in some respects) a 'collective' and viewed the

respondents as citizens with entitlements and obligations, thus taking a citizenship approach[xii].

Social constructionism another element of the conceptual framework of the study, examines meaning and interpretations and places the origins of these within a social context. It explains much of the issues relating to identity and the self (see section 3.8). Cheston and Bender (1999) state that a social constructionist viewpoint allows the person with dementia to maintain a sense of personal and social identity through discursive and other means. Many of the losses in dementia are attributed to changes in the person's relationships with others, as the person's social persona is constructed only through the cooperation of others. "Social constructions of dementia and dementia care influence the attitudes of professionals, informal carers, and people living with dementia themselves, as well as the relationships that develop and the services provided" (Kümper et al, 2005: 1200). Therefore, social constructionism is an interesting lens through which to examine health and social care systems, as this thesis does. Much of the literature review to follow has a strong social constructionist emphasis (see specific Sabat's work in section 3.8).

3.6 The Lived Experience

The following section examines the literature on how people understand and cope with the changes in their life as a consequence of having dementia at an individual and personal level. Central themes identified in this literature include: awareness of the illness, changes in identity and views of the self, coping strategies and management techniques. A second body of literature looking at how people living with dementia interact with their social world and how, in turn, other people influence and shape the experience of the illness is also reviewed. Central themes identified within this literature are stigma, social engagement, participation, activities and

[xii] It can be argued that as citizenship emphasises self-cognisance it is an approach that is more successful for those in the earlier stages of dementia.

withdrawal, changing roles, elements of selfhood and relationships with others.

The first question to be answered concerns the meaning of the lived or subjective experience of dementia. Firstly, it should be noted that dementia is a highly individualized and complex process (Steeman et al, 2006: 730). Secondly, the lived experience is concerned with somebody's opinions or feelings rather than 'facts' or concrete material evidence. For this reason, it is difficult to quantify or calculate. It relates to a person's sentiments, their emotions, attitudes, moods and opinions. On the topic of the subjective experience, there is a difference between the (externally) perceived and the lived reality. Froggart (1988:132) states: "from the outside it is very easy to define confusion. To the person concerned it is not confusion but an episodic mixture of forgetfulness over recent events, absentmindedness and internal preoccupations with thoughts and day dreams". The experiences of the observer and the person living with dementia are different, and it is only through listening to people that we can begin to grasp what their experience is like (Froggart, 1988). Therefore, other peoples' perceptions of the lived experience are not enough to give us real insight into dementia.

In terms of service evaluation, Cotrell and Shulz (1993) argue that worldwide, there is also a lack of involvement of people living with dementia in policy and service development. There is a dependence on proxy reporting to gather information in these areas. Proxy reporting occurs when significant others and/or family members are asked to report on their own experiences of dementia or on their opinion of the other person's lived experience. There are difficulties with this approach as care-partners might not have a complete understanding of how the person with dementia is feeling and they may not have accurate knowledge about their service use (Aggarwal et al, 2003: 196).

In the late 1980s considerations of the lived experience of dementia began to appear in the literature (Froggart, 1988; Lyman, 1989).

Lyman (1989: 604) called for social research to consider people living with dementia as social actors, people who live with impairment and interact within a series of socially constructed environments, in this way examining the social factors of dementia. This was a move away from the medicalisation of dementia. Froggart (1988) investigated the feasibility of including people living with dementia in the research process by carrying out exploratory work with three women with dementia. She concluded that as we learn more about dementia we begin to view it not only as an incurable disease but as an illness where experience is based on unfavourable circumstances. These advances, combined with Kitwood's (1993; 1997a) work on person-centred care have resulted in an increase in original research that examines the lived experience of dementia.

The increase in published research on the lived experience occurred in conjunction with an increase in the number of autobiographical accounts of dementia (Bryden, 2005; Davis, 1989; DeBaggio, 2003; McGowin, 1993; Sterin, 2002; Truscot, 2003). The autobiographical accounts listed here were all written by people with early-onset dementia. The authors were well educated and during their working lives they had high levels of responsibility (Davis, Bryden, DeBaggio, McGowin and Truscot). For example, Thomas DeBaggio was a published author and journalist. It can be argued that it is because of these traits and experiences they were well placed to write their own accounts, yet they can also give some insight into the lived experience for people with later on-set dementia, people who had non-professional work histories and less education.

Organisations, groups and forums run by and for people living with dementia is another facet of the growing knowledge base. They have provided further insight into the array of capabilities and the often hidden potential of people living with dementia. These groups and organisations have also given researchers much to think about. They have encouraged the active voice of people living with dementia and are beginning to play a role in lobbying for their rights and the development of appropriate policies and practices.

Examples of these include the Dementia Advocacy and Support Network (DASN International), established in 2000, which is a worldwide Internet forum run by and for people living with dementia dedicated to improving quality of life. Another group, The Scottish Dementia Working Group (SDWG), partly funded by Alzheimer's Scotland, is also run by people living with dementia. They campaign for improvements in services and challenge attitudes towards the illness.

Despite advancements in original research, autobiographical accounts of dementia and developments in medicine and psychological understandings of dementia, people living with dementia, though sometimes heard, are rarely listened to (Harris, 2002). Steven Sabat (2003), a Professor of Psychology and a prominent author on Alzheimer's disease, concurs with Harris and feels that it is still fundamentally important to gather information on the subjective experience of dementia in order to gain a more informed understanding of its effects and to find ways to enhance the quality of life of people with the illness.

3.6.1 Original research on the lived experience

With greater strides being made to elicit the views of those with dementia, particularly those in the early stages, in combination with increases in original research, it is reasonable to believe that many people living with dementia are able to give meaningful and coherent accounts of their experiences. Through this literature review, a number of original pieces of research on the lived experience came to light. These were roughly grouped into thematic categories as follows: (i) the meaning of everyday life for people living with dementia (Gillies, 2000; Holst and Hallberg, 2003; Menne, Kinney and Morhardt, 2002; Steeman et al, 2007), (ii) illness experience and representation (Harmon and Clare, 2006; Phinney, 1998; Svanström and Dahlberg, 2004), (iii) symptomatic experience and awareness (Phinney, 2002; Phinney et al, 2002; MacQuarrie, 2005), (iv) awareness and insight into dementia (Clare, 2004a; Clare, 2002b; Froggart, 1988; Howorth and Saper, 2003; Hutchinson, Leger-

Krall and Skodol Wilson, 1997; Seiffer, Clare and Harvey, 2005), (v) relationships with others (family and friends) (Langdon, Eagle and Warner, 2007; MacQuarrie, 2005; Snyder, 2001), (vi) thoughts about the future (MacQuarrie, 2005; Snyder, 2001), (vii) meaningful activity (Snyder, 2001), (viii) coping (Bahro, Silber and Sunderland, 1995; Clare, 2004a; Dröes, 2007; Gilmour and Huntington, 2005; Harris and Durkin, 2002; Keady and Nolan, 1995a/b; Pearce, Clare and Pistrang, 2002; Preston, Marshall and Bucks, 2007), (ix) gender specific coping (specifically among women with dementia) (Van Dijkhuizen, Clare and Pearce, 2006), (x) care services and the experiences of dementia (Aggarwal et al, 2003; Beattie et al, 2004; Proctor, 2001), (xi) selfhood and identity (Cohen-Mansfield, Golander and Arnheim, 2000; Sabat, 2002; Small et al, 1998) and (xii) losses associated with dementia (Gillies and Johnston, 2004; Ostwald Dugglebury and Hepburn, 2002).

Steeman et al's (2006) review of the literature on the lived experience of dementia looks specifically at published work from the early 1990s to the mid-2000s. They outline 33 articles on this subject, 28 separate studies and 21 different research samples. All are qualitative enquiries and the majority (ten) are phenomenological. Other theoretical approaches include grounded theory, biographical and emergent fit and two are longitudinal in nature. Steeman et al (2006) identify a number of key findings which are common across most of the studies reviewed, namely: early-stage dementia is highly individualized and complex and awareness and interaction with family and professional caregivers strongly influence the lived experience for individuals. According to these authors the influence of other factors such as gender, age, education, personality, type of dementia and relationship with family remained unclear. They (2006: 735) also identify the following common features in different studies: uncertainty, the importance of autonomy, meaningfulness and the struggle between self-protection and self-adjustment. Their review highlights the fact that people living with dementia go through a transitional process consisting of three phases: pre-diagnostic, diagnostic and the post-diagnostic phase. People notice changes

and search for meaning across these three phases. Other findings show that people with dementia commonly integrate it into their daily lives in silence. How family members cope with the onset of the illness also affects the coping ability of the person with dementia. Cognitive change has an effect on a person's sense of identity, their membership in society and their feelings of security and autonomy. Some of these common effects were negative. However, these authors also found positive outcomes from the dementia experience, where it can be integrated into a person's life in positive ways and mechanisms can be adapted by all stakeholders involved to deal with the illness effectively. Over time, the illness can therefore become less threatening.

The majority of people included in these original pieces of research were willing to communicate their experiences (Steeman et al, 2006: 735). Can it be assumed that these accounts accurately reflect the experiences of those who are unwilling or unable to communicate their own experiences? Providing informed, meaningful consent to become involved in research requires willingness on the part of the person with dementia to talk about him or herself and to have some level of insight into their experiences. Whether they represent the voice and views of people who are unable or unwilling to express their own experiences is not clear (Steeman et al, 2006: 735).

Despite the current international research focus on the person living with dementia as the main informant in psychosocial research on dementia, in Ireland there has been a limited body of research that has undertaken this practice (Cahill et al, 2008; Cahill et al, 2006). As far as I am aware, no research has been carried out in Ireland on the lived experience of dementia or on the social implications of having dementia. There is a greater need now, more than ever to involve in research those who experience and understand the effects of the illness e.g. those with dementia. Changing population patterns and population ageing have resulted in increased life expectancies and a subsequent increase in the prevalence of dementia (McColgan, 2004). Therefore, the continuation of this type of research is essential.

There were a number of dominant themes that emerged across a broad range of studies, namely, awareness, self and coping. If this literature review is to truly reflect advancements being made in understanding the lived experience, a further investigation of these themes is needed and the following sections examines them in detail.

3.6.2 Including people living with dementia in the research process

Including people living with dementia in research is no longer as new and innovative as it once was. However, this review shows that research on this topic is underdeveloped in Ireland. The international literature suggests that to do work in this area, one should use qualitative methods and conduct more than one interview with the person. More than two meetings have been identified as good practice. It has been shown that people living with dementia can be accurate informants of their lived experience, particularly when findings across a range of studies are consistent.

Dementia is a complex and extremely individualized process, therefore the use of innovative design is advocated. Methods need to be flexible and adaptable to each research informant. Different qualitative methods were used in the literature reviewed in this chapter and no methodological gold standard was identified on including people living with dementia in research.

3.7 Awareness

It is not accurate to assume that people living with dementia have no awareness[xiii] or insight[xiv] into their dementia (Phinney, 2002b) and in recent years an increase in the number of original research studies have highlighted this (Bahro, Silber and Sunderland, 1995; Clare, 2002; Cotrell, 1997; Dröes, 2007; Howorth and Saper, 2003; Marková et al, 2005; Mullen et al, 1996; Phinney, Wallhagen and Sands, 2002, Zanetti et al, 1999). These authors demonstrate that people living with

[xiii] Awareness is having knowledge of something because you have observed or been told about it.
[xiv] Insight is the ability to see clearly into complex situations or subjects.

dementia can have high levels of awareness, particularly those in the early stages of the illness. Linda Clare (2005a/b; 2004; 2003; 2002a/b), a British Psychologist, has become a forerunner in the examination of awareness in people living with dementia. She contends that the nature of awareness is integral to the development of appropriate person-centred interventions. Awareness and insight into one's ability to function may be a more important factor in predicting ability to remain independent than the severity of the memory and cognitive impairment (Cotrell, 1997). Investigating awareness also shows us how people view their situations and their quality of life (Clare and Woods, 2005).

Levels of awareness differ for those with dementia compared to those without. Froggart (1988: 132) argues that at least in the early stages of dementia people have some insight and awareness of what is happening to them. Similar to Froggart, Foley (1992), a leading Professor of Neurology in the United States, states that there is still an insistence in some quarters that people living with dementia are unaware. However, he contends to meaningfully interact with someone who has dementia, particularly someone in the early-to-middle stages, at least in some cases the person is aware that they have intellectual decline, that their behaviour has changed, that their illness is progressive and that their illness has an effect on other people (Foley, 1992: 30). This is reiterated by Marilyn Truscott (2003: 13) who was diagnosed with early-onset Alzheimer's disease when she was 54 years old: "I have, like many people in the early stages of Alzheimer's disease, strong insight into my situation. I can judge that I have deficiencies and problems. I am therefore also aware of my deterioration, the increases in problems". It is interesting that a range of people from different backgrounds and ideological perspectives have reached the same conclusion, that awareness is present for many people living with dementia, particularly for those in the early stages. Therefore, unawareness should never be assumed when interacting with someone who had received a diagnosis of dementia.

Similarly to Foley (1992), Killick and Allan (2001: 262) state that awareness is not just about one's insight into having dementia. A person can be aware of many changes in their life, for instance

- Changes in their personality
- Emotional experiences, changes in ability to control emotions
- Changes in levels of anxiety, depression
- Spiritual values and beliefs
- Ability to use language
- Motor skills
- Physical health
- Behaviour of others
- The feelings of others
- One's status in the eyes of others
- Living circumstances
- That life is coming to an end

An individual might be aware of all or some of these. When a person appears to be unaware of the presence or extent of their dementia it does not mean they are unaware of other changes and the experience of this can have a profound effect. Awareness is therefore very complex.

Generally, there are two different schools of thought on awareness and dementia. The biomedical perspective views unawareness as wholly or primarily the result of the biological factors of dementia. The bio-psychosocial viewpoint sees awareness as a product both of neurological changes in the brain and psychosocial responses to having dementia. Despite a greater emphasis in the literature on awareness and dementia, there are few established findings on the topic (Clare, 2004b). This is due in part to the fact that there is no definitive explanation of unawareness. Definitions and causal frameworks span neurology, psychiatry, psychology and social science. If we do not have a common definition across disciplines it becomes even more difficult to measure (Zanetti et al, 1999); it is conceptually and methodologically complex (Downs, 2005: 381). To address some of the complexities of awareness, the following sections will look at meanings of awareness, awareness frameworks,

assessment of awareness, psychosocial investigations into awareness and displays of awareness through art and poetry.

3.7.1 What is the meaning of awareness?

Mullen et al (1996: 645) describe awareness as "insight, the awareness of and attitude towards one's own mental symptoms". Clare (2002b: 308) sums up awareness as "a product of psychosocial process in interaction with cognitive impairment". Insight is a term often used by psychiatrists to refer to the awareness people have of their mental disorders (Mullen et al, 1996: 645). Howorth and Saper (2003: 114), taking a psychosocial approach, state that one must get beyond the biomedical view of dementia as a disease process to view the person with dementia as actively trying to make sense of their world and 'insight', as traditionally construed, becomes an intrinsic part of a person's own sense of self. Similar to Howorth and Saper, a simplistic and comprehensible approach to awareness and unawareness is contested by Phinney (2002a). She argues that the classification of someone with dementia as 'aware' or 'unaware' provides a convenient, simple and easily comprehensible typology; however, this does not capture the richness and intricacy of the phenomenon. As a result, awareness should not be examined in isolation.

Over the years and across disciplines, awareness has often been termed and constructed differently. The different terminology can be summarized as: (i) Anosognosia - introduced by Babinski in 1914. This refers to unawareness or denial of hemiplegia (paralysis on one side of the body) experienced by people after stroke (Marková et al, 2005: 387). Currently, anosognosia is often used to refer to people with brain injury or other cognitive disabilities. (ii) Unawareness or lack of awareness - this occurs when a person (a) actively denies a difficulty, b) acknowledges difficulty but explains it away or c) fails to acknowledge that there is anything wrong (Clare, 2004a: 156). (iii) Lack of insight and denial of illness/deficit - these terms are usually used in psychiatric and psychoanalytic theories. Motivated denial and/or defensive denial are sometimes used to distinguish denial

from the general use of the term (Clare, 2004a: 156). 'General denial' refers to the refusal by a person to acknowledge an overt disease or deficit. 'Motivated denial' refers to the underlying psychological processes which cause the person to deny the presence of a disease or deficit (Marková et al, 2005: 388). Motivated denial is seen as a separate phenomenon from lack of insight or unawareness (Marková et al, 2005: 388). (iv) Symptom awareness – this is "the conscious capacity to reflect on, talk about and accurately describe those experiences attributed to one's illness" (Phinney, Walhagen and Sands, 2002: 79).

3.7.2 Framework for examining awareness

Similarly to definitions of awareness, explanatory and theoretical frameworks for understanding awareness span a number of disciplines and areas of learning. Marková et al (2005: 387) establish three distinct frameworks for the conception of awareness, namely the neurological, the general psychiatric and the psychoanalytic. Within the neurological framework, awareness is explained as "a unitary sense in that different degrees of awareness are equated with awareness of different aspects or types of the impairment rather than qualitative differences in awareness itself ... thus, the conceptualization of awareness is very closely linked with and to some extent determined by the neurological/neuropsychological impairment itself". However, arguments against this framework centre on awareness as not solely equated with cognitive functioning alone (Downs, 2005: 381). The second framework, the general psychiatric framework, comprises two main components, namely a person's awareness of change and their judgment concerning the nature of change. The person does not just have knowledge of the change as a result of a disease but they also know that this will have consequences for the self (Marková et al, 2005). The psychoanalytic framework contends that the person has a much deeper knowledge of the self, where the self is placed within the context of life experiences, understanding that there are different levels at which knowledge is generated, for example emotional, intellectual and cognitive (Marková et al, 2005: 388). Denial in this context is a coping

mechanism and boundaries to the concept of awareness are more deeply blurred in this last framework when compared to the other two. In this way it addresses some of the complexities of the experience of dementia.

In line with Marková et al, Clare (2004a) in her review of concepts and models of awareness considers neurological, neuropsychological and psychiatric explanations. However, it is her investigations into the psychosocial explanation that are most relevant to this thesis. Clare (2004a: 163-164) argues that to adopt a psychosocial approach to awareness, one has to consider the nature of self and the lived experience. Two key psychosocial approaches to conceptualizing the self therefore emerge, the social cognitive approach and the social constructionist approach. The first of these, the social cognitive approach, views the self as a complex, multidimensional cognitive construct, which represents beliefs, attitudes and information regarding the self. The second, the social constructionist approach, views the self as a historically situated construction emerging from social processes. The concept of self is examined within a social relationship framework and knowledge of the self is dependent on the social context and on the feedback of others. This theory is intrinsically linked to awareness, identity and the effect of others on the experiences of dementia. This theory therefore is very relevant to this thesis, as we must look also at the context in which someone experiences dementia and how others influence the experience. The self is examined in greater depth in section 3.8 of this chapter.

Similarly to a social constructionist approach to understanding awareness, Awareness Context Theory can be applied to dementia (Hutchinson Leger-Krall and Skodol Wilson, 1997). It can clarify some of the psychological and social explanations for varied levels of awareness within people living with dementia. Originally, this theory was presented by Glaser and Strauss in the 1960s to explain the management of dying. The focus of this theory is the context in which the person experiences the illness. Unless someone is always alone,

memory and cognitive disability occur in a social context with friends, family, colleagues, neighbours and so on (Hutchinson Leger-Krall and Skodol Wilson, 1997). Applying this to dementia, these authors (1997: 1401) state: "the context consists of the important conditions that influence how one acts, thus determining the awareness context. As the conditions change, so can the awareness context". This theory is made up of two elements, the actual knowledge or awareness of x (in this case the presence of dementia) and the revealing or concealing of this knowledge in varied situations with varied people. The authors present four awareness contexts, which can be applied to the awareness of the presence of dementia: i) Closed awareness (in the context of a social interaction, the person with dementia and/or those close to them are careful not to divulge to others information about the presence and deteriorating nature of their dementia). ii) Suspected awareness (those within the social interaction context suspect the presence of dementia in the person). iii) Mutual pretence awareness (participants in the interactional context know about the dementia, but pretend otherwise). iv) Open awareness (participants within the social interaction discuss the dementia openly). These authors conclude that often people living with dementia are treated like they are "not all there" which creates a closed awareness context. Delayed diagnosis of dementia also means that often it is too late to have an open awareness context as the illness is too advanced. The optimal context is an open awareness one.

It can be concluded from this investigation of the literature that the framework most relevant to this thesis is what Marková et al (2005) calls psychoanalytical and what Clare (2004a) sees as psychosocial. Killick and Allan's (2001: 262) approach is also very useful, where awareness can apply to an array of experiences as a result of living with dementia not just an awareness of the illness alone. Elements of the awareness context theory are also relevant to the psychosocial framework. However, Clare (2004a: 170) makes a relevant observation that there is a need for an explanatory framework of awareness which encompasses and considers neurological,

psychiatric and psychoanalytical models as one does not exist at this time.

3.7.3 Assessment of awareness

Similarly to definitions and explanations of awareness, the assessment of presence and level of awareness spans a number of disciplines. Despite the increased focus on awareness, there is no gold standard in its measurement, assessment or in determining levels of (un)awareness (Zanetti et al, 1999). A common approach is to examine differences using a memory questionnaire, examining the self-rating of awareness by the person with dementia and comparing this to a rating by another person, usually a care-giver ('collateral source') (Kazui et al, 2006; Lamar et al, 2002). Scores from these questionnaires are then calculated and a discrepancy score is accrued between the two answer sources, thus providing a score which can be used as an approximation of a person's level of awareness. In their study, Kazui et al (2006: 6) conclude that discrepancy scores are more accurate in measuring awareness than an evaluation of awareness by the experimenter. However, the perceptions of the collateral source, who would normally be a caregiver, can be affected by their level of responsibility and stress (Kazui et al, 2006: 6-7) and by the nature of their relationship with the person with dementia. These factors were not controlled for in Kazui et al's study. Contradicting Froggart (1988) and Foley (1992), Kazui et al conclude that even in the early stages persons with dementia were unaware of and underrated their memory impairment in daily life.

Two other commonly used ways to assess awareness are self-predictions of performance on memory tests[xv]. However, these approaches neglect the qualitative elements of awareness and are based within what Kitwood (1997a) calls the 'standard paradigm', the medical model. Psychosocial qualitative approaches to awareness and dementia have uncovered themes and

[xv] Tools for the measurement of awareness are the Clinical Insight Rating Scale (CIR), Guidelines for the Rating of Awareness deficits (GRAD), Memory Rating Awareness Scale (Clare et al, 2002).

understandings of awareness that often go undetected by more quantitative approaches.

3.7.4 Psychosocial qualitative investigations into awareness

Psychosocial investigations of awareness do not concur with the neurological findings mentioned in above. Unawareness varies too much between individuals for neuropsychological variables to fully explain awareness in all people living with dementia (Seiffer, Clare and Harvey, 2005: 535). In Seiffer, Clare and Harvey's (2005) study with 49 people living with dementia, the researchers used neurological, psychological and social frameworks, accepting that awareness can vary between and within individuals, and not accepting that awareness automatically declines as the person's dementia progresses. They conclude that at different points in time, unawareness can reflect varying contributions of psychological, social and neurological factors.

Alison Phinney (1998; 2002a/b), a Professor of Nursing in British Columbia, in her work on understanding dementia through embodied narrative, has used in-depth interviews and observations of people living with dementia and their caregivers. Her (2002a: 52-68) findings show that the experiences of the symptoms of dementia can be classed into five groups: (i) 'I can't remember', (ii) 'I worry about getting lost', (iii) 'everything is more difficult', (iv) 'conversations don't always fall into place' and (v) 'I'm sort of oblivious'. Findings from this study show that even if people are unaware of their dementia or of the deteriorating nature of the illness, their awareness of symptoms and awareness of the development of deficits is common. Phinney (2002a: 50) reflects on the appropriateness of viewing a person's experience of symptoms through an awareness framework: "the way we have traditionally viewed AD as a disease of cognition in which the ability to self-reflect breaks down. Symptom experience, regarded as an issue of (self) awareness becomes yet another indicator of decline rather than an expression of the richness and complexity of the person's illness experience". Symptomatic awareness can be viewed as a person's

experience of symptoms yet it is not necessarily connected to their awareness of the nature of the illness, the dementia itself. To understand dementia requires an investigation into how symptoms are lived and how people articulate this experience. This needs to be carried out despite the difficulty for people living with dementia to articulate a narrative understanding of what is happening to them; a difficulty with narrative does not equate with total lack of awareness (Phinney, 2002a/b).

In Beattie et al's study (2004: 363) of 14 younger people living with dementia the findings show that insightfulness and awareness of deteriorating memory is a common experience for respondents. Self-awareness of their memory problem is often associated with coping with a sense of being different despite the overwhelming desire to be treated like an ordinary person. This would suggest that although people living with dementia may not signal their level of unawareness through direct discourse, talking about the effects of symptoms, of being different to their former self and being different to those around them, is evidence of awareness, awareness of the presence of change. Phinney (2002b: 331) concurs with this, stating that awareness is "constituting a way of being in the world, as an expression of lived experience that may not be articulated through narrative". She further stresses the need to place importance on how people describe and in what way they tell others of their experiences, how they bring order and meaning to their involvement in the world.

A study by Phinney, Wallhagen and Sands (2002: 89) looks at three different levels of meaning on awareness and unawareness of symptoms which exist for people with mild dementia, namely (i) 'everything works more slowly' – narrative of awareness; (ii) 'it's just old age' – narrative of unawareness (iii) 'it does not stick in the brain' – narrative of mixed awareness. They conclude that even in the early stages of dementia, symptomatic awareness can vary noticeably both across and within individuals. Similarly to Phinney, Wallhagen and Sands (2002), Foley (1992: 40-41) categorises respondents with

dementia into three groups: (i) those that are fully aware of their illness and of their intellectual capacity: "they preserve an awareness to some degree through the course of their disease", (ii) those that have no awareness of any deficiency in their intellectual state and act accordingly, even as they deteriorate and (iii) those who are aware something is wrong but choose to deny it and establish ways or schemes to conceal the illness. The experience of awareness is therefore not the same for all people, but the presence of awareness should not be discounted automatically. As a result, the use of qualitative approaches is encouraged in any investigation into a person's awareness of their illness (Howorth and Saper, 2003: 114).

3.7.5 Consequences of awareness

The review of the literature uncovered a number of consequences relating to awareness. Assumptions made by professionals and service providers regarding (un)awareness can lead to poor standards of care and the possible exclusion of people living with dementia from discussions about their future (Howorth and Saper, 2002). Another consequence of assuming unawareness can, in some cases, be the creation of negative relations between caregivers and care receivers (Seltzer et al, 1997). When people do not notice their symptoms it can delay the search for a diagnosis (Kazui et al, 2006) and can result in potentially hazardous situations arising, where the person places him or herself and others in danger. Examining levels of awareness can have consequences on clinical practice, where assessments can be uniquely tailored depending on the person's degree of symptomatic awareness (Phinney, 2002a). Clare et al (2004) contend that people with higher expressed levels of awareness of difficulties have better outcomes in relation to cognitive rehabilitative interventions.

3.7.6 Expressing awareness

This section on awareness has outlined reasons why people may not express their awareness. Killick and Alan (2005: 271) state that the person may try to express their awareness in forms that are more difficult for others to understand. Language for instance is only one

form of communication. They suggest that if people are given the right type of support and opportunities they can tell us a lot about their understanding of their circumstances through the use of the arts. John Killick has worked extensively with people living with dementia, eliciting their experiences through art and particularly through poetry. The following is a poem entitled Couplets, a transcription of the words of someone with dementia as recorded by Killick (2000), it illustrates how we can gain insight into the experience through alternative methods;

"I can't get comfortable
In my mind I can't get comfortable.
How come you stop talking
when you're talking – you shouldn't do that...
And now I'm going to ask you a question:
Would you like to live like this?"

This poem suggests that the author is aware of changes and recognises that his or her verbal communication skills have changed. The situation is difficult for the author who invites readers to consider how they would feel in this situation. Communication is often effected with the onset of dementia. This fact can result in assumptions being made that people lack awareness and indeed capacity because they are not able to communicate their experiences and attitudes. It is then up to others to investigate and use other means of communication and understanding to interpret the views and experiences of those living with dementia.

3.8 The Self and Identity

Reviewing the literature has shown that the self is inextricably linked to the issue of awareness. Findings from a study carried out by Langdon, Eagle and Warner (2007: 992) show that people living with dementia fear a loss of social status and familiar work and social roles with the onset of dementia. In this way they are less comfortable that people outside of their 'private worlds' know they have dementia. They fear they will be treated differently as a result. In this way, strategies for maintaining the self are linked to aspects of

(un)awareness, where the person can be motivated to deny the presence of an impairment. Indeed it has been said that psychosocial investigations into dementia and awareness have to consider the nature of the self and the lived experience (Clare, 2004a).

A parallel can be drawn between Personhood and self-identity where Personhood is "Individual/personal power over life choices, the capacity for interpersonal relationships and interaction with others sharing the same culture, awareness or consciousness of the self as a social actor expressed in and through language and encompassing feelings and emotions about self-pride, honour, satisfaction" (Evans, 1999: 33). Social roles throughout the life-course support the essence of identity about the self (Cheston and Bender, 1999), and they also reflect status. Snyder (2006: 268) argues that social constructions of dementia have resulted in phrases like 'the loss of self', the person being an 'empty shell'. She suggests that these assumptions affect communication and how the person is treated: "If we communicate with people living with dementia 'as if' their self is diminished, we are less likely to hear the intact messages that are expressions of personal identity".

Controversially, Hill (1999) asks whether we can relate to people living with dementia in the same way as before when all of their practical competencies and emotional responses have changed, Is the self still intact? This review briefly examines these questions. In doing this, two main questions emerge, namely: What is the self and how is the self affected by the onset of dementia?

Steven Sabat (2001: 17), one of the leading investigators into the self and Alzheimer's disease, suggests that there are three aspects to the experience and expression of what he terms 'selfhood' for the person with Alzheimer's disease. Taking a social constructionist viewpoint, selfhood can be outwardly expressed in a number of different ways. Sabat describes these as Self 1, Self 2 and Self 3.

- Self 1 is the self of personal identity: sense of self is expressed as a singular person, a unique individual, a person who is continuous and holds a single point of view in the world of time, space and object. This remains intact throughout the whole experience of dementia.
- Self 2 is the self made up of mental and physical attributes, which can also remain intact throughout the experience.
- Self 3 is the person's socially presented personae. It differs from the other two as it demands interaction with the social world. Sabat gives an example of Self 3 as a person who is a mother, a professional, a good neighbour. In each case the person is viewed differently but it is the contribution of the viewer that establishes the distinction. Similarly, people may know each other through one of these personas as they are invested in one aspect of the other person's life and not in others.

Self 3 follows a framework of social constructionist theory and gives an explanation of social identity and maintenance of self where the social persona of Self 3 is constructed though what Sabat (2003: 8) calls the "mutual cooperative interaction of persons". This self can be lost, not because of the biological change due to Alzheimer's disease but because of how people are treated by 'healthy' others. Holst and Hallberg (2002) suggest that the self is affected by the ability of the person with dementia to reach out to others. Their findings show that persons with dementia can feel they are no longer acknowledged as a person because they have lost this ability.

Aquilina and Hughes (2006: 151) simplify the selves of social constructionism and incorporate each of the three selves into what they call the 'inner' and 'outer' selves. The first is the private subjective experience of self-awareness, apparently dependent on biological structures. The second is the public observable self, which depends on psychosocial structures including social relations, culture and language. They state that the three selves of the social constructionist model traverse the gap between the inner and outer selves. Self 1 requires a public utterance of the personal pronoun but reflects an inner process. Self 2 is made up of outer physical attributes

and mental inner attributes. Self 3 manifests as public yet it involves an inner act, where the person can be viewed as a mother, neighbour etc.

Cheston and Bender (1999), like Sabat, argue that a social constructionist viewpoint helps the person with dementia maintain a sense of personal and social identity through discursive and other means and many of the losses associated with dementia are attributed to changes in the person's relationships with others, as the person's social persona is constructed only through the cooperation of others. As a person's dementia develops, the assumption is often made that their capacity and capabilities are failing. Sabat (2003: 8) suggests that the person with Alzheimer's disease is as much "a prisoner of dysfunctional treatment" as they are of the neuropathology of the disease. Constructing a new, and/or maintaining, an existing social persona once the onset of dementia occurs can give worth, help maintain self-identity and promote the person as a valued individual.

In their study with 12 people with early-stage dementia, Preston, Marshall and Bucks (2007: 133) conclude that changes experienced as a result of the onset of dementia create a discontinuity between respondents' past and present self. Therefore, in order to examine self and identity, the changes that are experienced after the onset of the illness have to be examined. Not necessarily accurately but traditionally identity in relation to dementia has been linked to loss, where loss comes from both internal recognition (the lived/subjective experience) and external reactions, where others change their attitudes and behaviour towards the person with dementia (the objective and observed) (Gillies and Johnston, 2004: 436). Symptoms of dementia (memory, thinking, language, well-being, personality) disrupt continuity and this component of personal identity is compromised (Gillies and Johnston, 2004: 440).

3.8.1 'Losses'

Ageing itself is associated with changing roles, for example leaving paid employment (retirement), changing roles within the family, changing health status and being bereaved of close friends and relatives. However, there are additional changes distinct for the person living with dementia. Gillies and Johnston (2004: 438) suggest that personal independence can be lost due to changes in bodily functions and decreased memory and cognition skills. These losses can be further exacerbated by the removal of the opportunity for decision-making on the grounds of perceived or bestowed incompetence. These losses can cause depression, increased anxiety and feelings of uselessness (Jaques, 1997).

A number of other losses have been identified in the literature as: (i) loss of dignity (Moody, 1992: 87): "It is shame, a loss of dignity in the eyes of others, a loss compounded by the fact that others adapt to the situation, become accustomed to the patient's incompetence and finally come to consider the patient less than a person". (ii) Loss of respect from others: as a person living with Alzheimer's disease Sterin (2002: 8) states: "the condition does more than rob one of the short-term memory, inconvenient and aggravating as that is, much worse, it robs one of dignity and the respect of others". (iii) Loss of friends and relatives, who perhaps "did not understand, did not know how to relate to the person with dementia or found the deterioration too painful" (Aggarwal et al, 2003: 193). (iv) Loss of self-esteem (Aggarwal et al, 2003; Gillies, 2000), which in Gillies' study resulted in the loss of ability to engage in interpersonal relationships. (v) Loss of independence, due to physical impairment (Gillies and Johnston, 2004). (vi) Loss of role (Gillies and Johnston, 2004). (vii) Loss of autonomy (MacQuarrie, 2005).

There is a tension between being an agent and being objectified, where agency equates with independence and control over one's life and objectification means dependency upon others and a loss of autonomy in parts of the person's life that previously had been in their control (MacQuarrie, 2005: 433). Most of these losses are a result of

interactions with other people, and how the person living with dementia internalises these interactions having an effect on their own identity and sense of who they are.

Many of these 'losses' can be attributed to elements related to social constructionism, where the person is no longer viewed in the same way by others and the person no longer views themselves in the same way. A further example of this is from Aggarwal et al (2003: 195), who suggest that loss as a result of dementia can accumulate into social isolation. These authors state that people with disabilities can internalise restrictive views thus thinking of themselves in these terms, taking on these perceptions, behaving in ways that are expected of them. It "becomes a self-fulfilling prophecy". The accumulation of these losses can have distinct effects on the person's own sense of who they are and what they are able to do, whether this is a true reflection of their own abilities or presumed ability placed on them by others.

3.8.2 Participation and the self

Activity is another way of reinforcing self-identity, with a focus on continuation between the past and present self (Preston, Marshall and Bucks, 2007). A study by Preston, Marshall and Bucks (2007) on coping with dementia shows respondents referring to ongoing use of skills and enjoyment of many of the same activities they previously carried out. In this way activities promote the continuity of the self as the illness progresses. For people living with dementia to continue to participate in this way requires activities that are familiar, activities that allow the person to feel successful (Dowling, 1995). They should focus on retained abilities.

Pulsford (1997: 705-706) states that activities can be therapeutic, for example 'restorative' activity such as cognitive therapy, reminiscence therapy, reality therapy, validation therapy or leisure or social activity which may enhance quality of life and well-being, where the purpose is to encourage enjoyment and interaction. For people living with dementia meaningful activity can also be found in

what previously would have been seen as mundane or ordinary events: "the moment-to-moment experience of memory loss can result in opportunities for spontaneous excitement or appreciation" (Snyder, 2001: 18).

In the preceding section, the context of identity was largely characterised in terms of 'loss'. However, the lived experience of dementia does not have to be a series of losses. Logsdon (2002: 83) states: "although Alzheimer's disease is a devastating illness, many individuals are able to find meaning and quality in their lives despite the progression of cognitive, memory and functional deficits. By identifying and providing appropriate services, health care providers, family members, professional caregivers and others can make a difference in the lives of those with Alzheimer's disease". How others interact with the person and what formal and informal supports are available can infuse positive elements within the dementia experience. If selfhood is understood within the context of Personhood, then as Kitwood (1993: 541) states the person with dementia "should be viewed as a person in the fullest possible sense: he or she is still an agent, one who can make things happen in the world, a sentient, relational and historical being".

3.9 Relationship with Others

It has been shown that social and psychological factors affect awareness and influence how people living with dementia interact in their social world. Sabat's concept of the persona in Self 3 is the one most affected by the onset of dementia. How people then interact and engage with others (both the role of the person with dementia in this engagement and the roles others take on) are extremely important in investigating the lived experience. Social constructionists state that symptoms observed in dementia are not solely a result of brain pathology (Sabat, 2001) but often arise and can be aggravated by external factors. This section examines this further by looking at how other people help shape the experience of dementia.

3.9.1 Social engagement

Outside of the 'losses' experienced as a result of developing dementia and the changing social interactions people may experience, the importance of social engagement and the maintenance of social networks[xvi] can not be disputed. They are important for the continued participation of the person in social activity. Berkman and Clark (2003: 289) state that "social networks form a web of associations that serve a myriad of functions, including the provision of support and access to material resources". Bassuk, Glass and Berkman (1999) highlight a benefit of social networks and social engagement as the greater availability of emotional support from relatives and friends, particularly as the person's dementia develops. It is commonly accepted that having an extensive social network can protect against dementia (Fratiglioni et al, 2000). Based on findings from their study Bassuk, Glass and Berkman (1999) conclude that the chance of developing a memory and cognitive impairment is approximately twice as high for those respondents who report no social ties, in comparison to respondents who had five or more ties. There is little empirical evidence, however, to suggest that social networks have an effect on the progression of the illness after its onset.

Slater's (1999: 97) concept of belonging is useful when exploring social engagement where belonging for most people develops "first within a domestic context, second within a community and educational setting and third through engagement in occupational and leisure activities...it is mainly within the relationships which are formed that our self-esteem and sense of Personhood and place are nourished and sustained". There is evidence in the literature that the social networks of people living with dementia are family and household centric (Kirby et al, 2000; Wenger, 1994). People living with dementia have less contact with friends, neighbours and community

[xvi] Social networks are "linkages between individuals with whom one has a close family relation and/or affection. This means that friends and close colleagues are part of the social network, but also that one's parents or siblings are always a part of the social network" (Due et al's, 1999: 662).

groups. As a result, the family tends to become the main social network for the person.

Inclusion[xvii] also incorporates an element of social connectedness, which is the construction and successful maintenance of reciprocal interpersonal relationships (Ware et al, 2007: 469). It has already been shown that social status and societal roles (familial and work) can affect a person's sense of self and Identity, their sense of value as a member of society and their feelings of security and autonomy (Steeman et al, 2006). Therefore, dementia can result in isolation from others and from self (Smith, 1992).

3.9.2 Social relationships

Most people do not live in isolation and the majority are engaged in meaningful relationships. Snyder (2002) argues that barriers in communication, withdrawal and threats to the experience of belonging can affect the relationships people living with dementia have. Through researching this issue, Snyder (2002) outlines a number of key themes that influence how people living with dementia relate to other people, namely: (i) barriers to communication (verbal and language difficulties, difficulty tracking discussions, real or perceived responses from others), (ii) devaluation (threats to self-esteem), (iii) the fear of being a burden, (iv) impact of role changes, (v) loss of autonomy (threats to freedom and independence - people living with dementia can become argumentative and defensive with family members whom they perceive as bearing authority over them), (vi) mutual adjustments (each stakeholder in the dementia experience has to cope with the illness) and (vii) reliance on family for basic survival and wellbeing.

Steeman et al (2007: 119), in their study with 20 people living with dementia found that respondents were constantly struggling to remain someone of value. This struggle was partly promoted by their interactions with others. Sterin (2002: 8), as a person with dementia,

[xvii] There is a large body of research on the social inclusion of older people but this is not the main focus of this thesis and as a result a more extensive investigation into this issue is not undertaken here.

explains how other people made her feel. She felt she was being labelled through what she called gestures of dismissal, acts of smothering and being made to feel invisible. In this way other people's awareness and understandings of dementia can have an impact upon the individual and create negative interactions: "If we make assumptions about the person with the disease that are based primarily on his or her defects, to the extent that we assume that the person has lost his or her self, our behaviour toward that person will be affected by such interpretations and assumptions and we will treat the person very differently from the way we would treat them if we assumed the opposite" (Sabat, 2002: 90). Snyder (2002) identified a number of other elements of relationship which can affect the person with dementia:

- feelings of being ignored can be demeaning for the person with dementia
- negative responses from others can lead to withdrawal
- people living with dementia can become over-stimulated in social situations
- increased suspicion of others can lead to social withdrawal
- people living with dementia can re-establish connections by getting involved in community programmes which can counteract feelings of devaluation and reduce levels of withdrawal and isolation.

Similarly to Snyder and Sabat, Kitwood (1993: 542-543) contends that 'the problem' of dementia does not lie exclusively with the individual who has a neurological impairment. He argues that the person with dementia is also significantly disabled by society's negative attitudes towards him or her and by stereotyping and even professional nihilism. He terms this 'malignant social psychology' and contends that these malignancies go some way towards explaining the dementia process. He outlines elements of malignant social psychology as:

- Treachery – when others use dishonest representation or deception to obtain compliance from the person with dementia

- Disempowerment – when others do for the person with dementia what they are able to do themselves
- Infantilization – when others treat the person with dementia like they are a child or a baby
- Condemnation – when others blame the person with dementia: 'the attribution of malicious or seditious motives' especially when the person with dementia is distressed
- Intimidation – using threats, commands, or physical violence, fundamentally abusing power
- Stigmatization – making the person with dementia a diseased object, through the use of verbal labels the person with dementia becomes an outcast
- Outpacing – giving information faster than the person with dementia can process
- Invalidation – ignoring or discounting the person's subjective state
- Banishment – removing the person from the human milieu, either physically or psychologically
- Objectification – the person is treated like an object that can be measured, pushed around, filled, drained etc.

First formulated in the early 1990s the concept of malignant social psychology was groundbreaking. It placed many of the interactions people living with dementia experience in a negative light and it was a catalyst for change in the care of people living with dementia.

In 'malignant social psychology' the person with dementia is a passive actor. However, in recent years there has been a stronger emphasis on the active role of the person living with dementia. For example, Snyder (2002) suggests that people living with dementia are often ambivalent about disclosing a diagnosis to other people; they are selective in who they disclose a diagnosis to, often doubting or denying the presence of the illness completely (see above section 3.7.1 which describes the process of motivated denial in greater detail). Denial or non-disclosure can change the nature of a relationship and how people interact with each others.

3.9.3 Stigma

Kitwood (1993) talks of the verbal labelling of people as the stigmatization of dementia. Indeed Sterin (2002) experienced labelling by others as a negative consequence of having dementia. It is often argued that people living with dementia face the double stigma of ageing and mental illness (Satorius, 2003; Werner and Davidson, 2004). Possible effects of stigma for older people are outlined by Sartorius (2003: 669) as: difficulty accessing health care, isolation from family and from members of their community and loss of self-respect.

Stigma is a situation where an individual is disqualified from full social acceptance (Goffman, 1963). Charmaz (1983) contends that people living with dementia experience stigma as many live restricted lives which can result in the all-consuming retreat into the illness. The effect of stigma is not just felt by the person with dementia but by their families and those who care for them (de Mendonça Lima et al, 2003). A consequence of felt and enacted stigma is that people living with dementia are often reluctant to tell others that they have the illness (McGowan, 1993; Snyder, 2002). From reviewing the literature a number of factors have been identified which can contribute to this stigma: (i) the negative portrayal of dementia in the media (Bond and Corner, 2001), (ii) lower levels of diagnosis by health professions (Vernooij-Dassen et al, 2005), (iii) the status of dementia as a mental illness, (iv) the ultimate cognitive decline of the person, (v) the view that dementia is a death that leaves the body behind (Evans, 1999) and (vi) assumptions that people living with dementia are unaware of what is happening to them. This notion of stigma is supported by Truscott (2003), who herself has dementia and struggles with the stigma of having received a diagnosis. She tells of the fear others have of the illness and the need for greater education about dementia to combat this ignorance and lack of awareness.

It is interesting and insightful to examine felt and perceived stigma in other mental illnesses and to compare these with the stigma experienced by people living with dementia. However, studies show

that levels of stigma vary across categories of mental ill health (Crisp et al, 2000; Mann and Himelein, 2004). As a result 'blanket terms' such as 'mental patient' which Mann and Himelein (2004: 187) feel have dominated research on psychiatric stigma, are not useful. In some respects people living with dementia have avoided the stigma of being termed a 'mental patient' due to the common belief that dementia is a normal part of ageing. However, this, too, is a double-edged sword, as being older leaves the person open to age-related stigma.

Crisp et al (2000) examined the stigmatisation of people with mental illness through a large-scale representative survey of the general population (N=1737). They examined the public's opinion on seven mental health illnesses namely, severe depression, panic attacks, schizophrenia, dementia, eating disorders, alcoholism and drug addiction. In relation to dementia, 60.6% of respondents said they perceived people living with dementia would feel differently to themselves, 52.9% said that people with the illness were unpredictable and 59.9% stated that people living with dementia were difficult to talk to. Questions were also asked about recovery and treatment, with 82.5% of respondents stating that people living with dementia never recover and 56.4% said that there is no improvement if the illness is treated. Questions regarding the person with dementia 'pulling themselves together' and 'only having themselves to blame' elicited little agreement from people interviewed in their sample, with only 4.2% and 4% agreeing with the above statements respectively. This survey also found that stigmatising attitudes were no less frequent among younger people. The authors conclude that because people feel that those with mental and in the case of dementia memory and cognitive illness are harder to talk to, feel differently from the way they do and are unpredictable those with a mental and/or cognitive health problem can experience social distancing and isolation. Social distancing ensures that a lack of familiarity with the experiences of people with mental health problems continues.

Werner and Davidson (2004) examined lay people's reactions to people with Alzheimer's disease, looking specifically at emotional reactions. Respondents (N=150) were asked to answer structured questions about a number of vignettes describing a person with dementia. The majority responded positively to the vignettes, reporting high levels of compassion (74.1%), concern (60.4%), sympathy (45.3%) and desire to help the person with dementia (71.9%). In 85.9% of cases respondents expressed low levels of anger, low levels of irritation (91.3%), disgust (93.8%) and rejection (85.8%) towards people living with dementia presented in the vignettes. A third of respondents specifically diagnosed the person in the vignette as having dementia (32%). The low level of adequate diagnosis prompted the authors to call for an increased effort by the public to recognise dementia. However, this study also shows that those people interviewed had high levels of compassion towards people they identified as having dementia.

Stigma, at a personally felt level can result in withdrawal from social activity and can create isolation and exclusion. However, it is not just the public's stigmatisation of dementia that needs to be considered. Vernooij-Dassen et al (2005) contend that stigmatisation by professionals is the over-riding factor which delays timely diagnosis of dementia. Professionals can seriously influence the diagnosis and treatment of dementia through the effect of stigma on service delivery and development. Another consequence of stigma is highlighted by Gilmour and Huntington (2005: 122) who state that societal stigma can prevent people actively seeking dementia-specific services such as those provided by Alzheimer's Societies. Care-givers and family members can also be reluctant to seek assistance from dementia-specific services.

The only study examining stigma and dementia in Ireland was carried out for the Alzheimer's Society of Ireland by the School of Nursing and Midwifery in Trinity College Dublin (Nolan et al, 2006: 92). One of the conclusions of this study is that people living with dementia and their caregivers often experience stigma which in turn induces isolation

from support networks. People in the study reported being subject to experiences and attitudes which made it difficult for them to access available systems and services. One of the limitations of this study, however, was that only one person with dementia was interviewed. Despite this, valuable data was collected on caregiver's difficulties when they encountered discrimination, devaluation and stereotyping of their loved one who had dementia.

Although the experience of stigma can be a consequence of having dementia, the literature suggests that it is not at the same level as mental health illnesses. However, people living with dementia can experience a double stigma, of old age and disability. With so many factors at work for the person with dementia (neurological, psychiatric and psychosocial changes and adaptations) how do they manage and cope with the onset and development of the illness? Changes in self identity and varying levels of awareness also influence how they cope with the illness.

3.10 Coping

The ways in which people living with dementia manage day-to-day and adjust psychologically and socially to changes in their life have important implications for improving their psychological well-being and quality of life (Preston, Marshall and Bucks, 2007). Examining coping responses to dementia provides greater insight into the processes of dementia and the lived experience. Dröes (2007) reiterates the link between awareness and coping by stating that until very recently, coping was neglected in systematic empirical research, as it was generally believed that people living with dementia had no insight into their illness and therefore did not implement any coping mechanisms. However, since the 1990s more research has been undertaken looking specifically at this topic (Bahro, Silber and Sunderland, 1995; Dröes, 2007; Pearce, Clare and Pistrang, 2002; Preston, Marshall and Bucks, 2007; Seiffer, Clare and Harvey, 2005; Van Dijkhuizene et al, 2006; Woods, 2001). A common theme identified in studies carried out on the lived experience is that

people implement strategies to protect themselves from the threat that dementia presents and in this way people living with dementia struggle with self-protection and self-adjustment (Steeman et al, 2006).

From a review of coping and stress, Nolan et al (1994) identify three main ways caregivers cope with dementia; (i) taking direct action to manage situations, (ii) creating an alternative perception of reality to manage the meaning of situations and (iii) managing symptoms of stress by use of relaxation methods. In a later study with ten people living with dementia, Keady and Nolan (1995b) found that all coping strategies implemented by respondents fell into one or more of the above three categories. They identified a number of specific strategies used by respondents, these were note taking, withdrawing from social and stressful situations, covering up and establishing a daily routine (Keady and Nolan, 1995b). Young (2002) found that there are certain active coping mechanisms that people implement, such as gathering information on dementia, enrolling in clinical trials and participating in support group meetings. A problem in Ireland is that there is not a standardized practice or national guidelines on disclosing a diagnosis (see Chapter Seven, section 7.4.1 for a discussion of the debate surrounding diagnosis disclosure). It could be argued that this hampers the implementation of these three coping strategies.

A reason for implementing coping mechanisms is that coping can be a way of taking control and maximizing functioning (Gilmour and Huntington, 2005). Coping can be perceived as maintenance or self-maintenance for the person. Coping strategies can be viewed as a way of moving on which occurs when people begin to cope with the changes and threats that the illness presents (Steeman et al, 2007).

Drawing on bereavement literature, denial is often a common reaction to perceived threat: "human beings have two primal reactions for dealing with threatening situations – fight or flight" (Kendrick, 1998: 60). In an earlier section on awareness, the theory of

motivated denial was presented. This is the implementation of psychological mechanisms which present as unawareness but are motivated methods for altered acceptance of the illness. Denial can be a response to the emotional reaction to having dementia. Parkes (1996) highlights denial and avoidance as common reactions to grief and as part of the process towards acceptance. Other common responses to grief that are seen in the dementia literature include anxiety, restlessness, fear, anger and guilt. The person can also experience feelings of loss of self.

3.10.1 Withdrawal

Aggarwal et al (2003: 195) concurs with Kendrick's theory of fight or flight, stating that withdrawal can be an understandable coping mechanism when presented with the symptoms of dementia, particularly in the pre-diagnosis stage. Holst and Hallberg (2003) suggest that this is partly due to people with memory and cognitive disability being unable to maintain interests but it is also a result of overwhelming negative feelings which make adjusting to new circumstances more difficult. MacQuarrie (2005: 438) views withdrawal from activities and social engagement as a way for people living with dementia to take control of what is happening: "this was a strategic reaction to the neurogenic changes, not a sign of being controlled by their deterioration".

People living with dementia can find some social environments over-stimulating and withdrawal can therefore be a natural consequence of this (Synder, 2001). They can have difficulty following conversations and smaller social groupings are often advocated for in the dementia literature (Goldsmith, 2002: 141). People living with dementia can follow conversation more easily when it is one-to-one. The progressive nature of dementia also causes a decrease in the maintenance of social interactions. However, in the early stages a person is better equipped to remain socially connected, but as the illness progresses the person is at greater risk of social isolation and withdrawal (Snyder, 2001). Stigma can also cause a person to withdraw for fear of the judgment of others (Synder, 2001).

It has already been shown that strategies such as denial can prevent people from entering situations or participating in activity where symptoms of their dementia may become evident to others. Howorth and Saper (2002) found in their study with 32 people living with dementia, that respondents often avoided social situations where perceived threats existed; they might be 'shown up'. In this way avoidance is used as a coping strategy. Holst and Hallberg (2003: 363) in interviews with 11 people living with dementia found that respondents reported feelings of shame and sadness at loosing the ability to share experiences with others. In this way they were becoming disconnected from those around them. People living with dementia often experience feelings of annoyance, anger, hurt, humiliation in front of others, shock, sadness and exasperation (MacQuarrie, 2005). These emotional responses are another cause for withdrawal from social contexts.

Depression is often associated with dementia, although it is not a symptom of the illness (Jacques, 1997). Experiencing depression can result in natural withdrawal and introversion. Truscott (2003: 14) states that depression in early dementia can be a result of boredom. It can be difficult for the person to find the motivation to do things as they combat an inertia which prevents them carrying out tasks. Frustration experienced when carrying out tasks is another possible cause for the person to discontinue the activity. It is difficult to determine whether withdrawal leads to depression or whether depression causes withdrawal.

3.10.2 Covering up

Another psychological theme identified in the coping literature was what Keady and Nolan (1994) describe as covering up: the person with dementia actively and consciously covers up symptoms of dementia until they can no longer keep up this strategy. It was seen as a way of avoiding the illness or covering up symptoms and changes as a result of its onset. Preston, Marshall and Bucks (2007) found a contrast between one group of respondents who avoided talking and thinking about their situations and covered up evidence

of any problems, and another group of respondents who spoke openly about their experiences. Similarly, Keady and Nolan (1994) found that respondents experienced personal achievement in successfully covering up their initial memory lapses. Respondents in Gillies' (2000) study attempted to disguise their difficulties through the use of evasive language, words such as 'possibly' and 'maybe' were commonly used; this was an attempt to disguise their confusion. It can be concluded that covering up is a common strategy for many people living with dementia.

3.10.3 Normalisation and comparison to others

Another noted coping mechanism was normalising the effects of dementia, where the person compared themselves to other people and other peoples' impairments. It is also common for people living with dementia to contextualize their memory and cognitive decline within the parameters of normal ageing (Gillies, 2000; MacQuarrie, 2005). 'Social comparisons' are strongly linked to impairment as a normal part of ageing, it is expected that there will be some cognitive and memory decline as one ages. MacQuarrie (2005: 437) states that "re-framing the symptoms of the disease through minimization and normalization strategies presses against the objectifying process of being identified as a patient with a disease". Another psychological coping mechanism often used by people is to compare their disability to those around them (Gillies, 2000; Langdon, Eagle and Warner, 2007; Pearce, Clare and Pistrang, 2002; Preston, Marshall and Bucks 2007) where "people living with dementia may selectively choose comparisons to positively enhance their self-esteem and preserve their social identity" (Langdon et al, 2007: 999). Comparisons can be a common way in which people develop views on situations and functioning (Harmon and Clare, 2006). These authors identified three types of comparisons; comparisons with peers who are functioning better, comparisons with others who have similar difficulties and comparing themselves to an earlier or past self.

3.10.4 Positive coping

In an earlier section the possibility of having some positive experiences of dementia was alluded to. Successful coping strategies have also been identified which do not rely on psychological mechanisms but are carried out in an open context. It can be argued that people living with dementia who positively cope are pragmatic and face the reality of their diagnosis (Harris and Durkin, 2002). They realise that the situation is beyond their control (Gillies, 2000). The following is a breakdown of the main findings from Harris and Durkin's (2002) study, where they identified 12 positive coping strategies used by respondents;

- telling other people
- positive attitude and self-acceptance
- adapting or replacing old roles
- developing practical strategies
- maintaining a connection with past activities
- going with the flow
- altruism
- being proactive
- anticipatory adaptation
- holistic practices
- drawing on spirituality

These are all positive strategies. The person may need to be proactive in addressing their illness. Jacques (1997) states that people living with dementia are often not proactive and are passive in their acceptance of the illness. This implies that people (i) are aware of having dementia and (ii) consciously choose to passively accept their situation. This negates aspects of the Personhood approach which outlines the effect of other people, the environment and other social and psychological factors which affect a person's experience of living with dementia.

The literature suggests that successful coping can be facilitated by informal and formal care-partners. Similarities between bereavement processes and the lived experience of dementia were referred to above (see section 3.10). Kendrick (1998) makes a number of

recommendations on how service providers can support people coping with bereavement. These can also be applied to service providers who support people living with dementia, namely: (i) facilitating the person to talk openly about their sense of loss, (ii) allowing the expression of strong feelings, (iii) helping the person to live independently, (iv) allowing time for grief, (v) treating each person as an individual and (vi) identifying common reactions, reassuring the person that their reactions are normal and providing continuous support over time.

Psychosocial interventions have proven successful in helping people cope effectively with dementia. Logsdon (2002: 83) states that "support groups and activity programs for persons with AD [Alzheimer's disease] can provide social relationships, a network of peers and appropriate pleasant events for individuals at all stages of the disease, as well as providing needed respite for caregivers...maintaining a positive focus on what the person can do, rather than constantly dwelling on what has been lost, appears to be a key to preventing depression and maintaining a high quality of life (QoL)". Focusing on retained abilities over loss of ability is important; it is in accordance with the social model of disability and upholds the principles of Personhood.

A number of studies identified humour as a positive coping mechanism to help people living with dementia (Keady and Nolan, 1995b: 2). Dowling (1995) identifies humour as a therapeutic technique as well as a cognitive exercise. Humour can also help to put things in perspective and defuse difficult situations and/or feelings (Preston, Marshall and Bucks, 2007). It can be a form of respite: "the ability to laugh at the seemingly absurdity of one's symptoms can transform an experience from the tragic to the comedic and provide those involved the welcome respite of a good laugh" (Snyder, 2001: 19). Caregivers can also benefit from humour, particularly when addressing aggressive or challenging symptoms/behaviours (Brodaty, 1997: 457).

3.10.5 Practical strategies

The literature shows that people living with dementia often implement practical as well as psychological strategies to manage and cope with the illness. Gillies (2000) identifies a number of strategies to overcome the practical problems of having an 'unreliable memory', such as the use of formal memory techniques to support memory, taking notes or keeping diaries to record important and useful information. These strategies can give control over "an unravelling world" (Gillies, 2000: 370). In terms of discourse and language, people living with dementia can implement strategies such as the use of word association (Preston, Marshall and Bucks, 2007) and the use of visual prompts to aid their communication (Keady and Nolan, 1995; Preston, Marshall and Bucks, 2007).

This thesis examines the lived experience of dementia within a broader socio-political framework. Sections 3.6 to 3.10 examined the literature of the lived experience of dementia the following section provides an overview of the Irish health and social care system and examines dementia-specific policy in greater detail.

3.11 Overview of the Irish Health and Social Care System

Part of this thesis is examining respondent's use of health and social care services. Therefore, a short overview of the current system of care is provided in this section. While the Irish health and social care system has some similarities to systems in other countries, it has a unique mix of public and private service provision. There are also no nationwide dementia-specific service plans. At the time of writing (2008/09), dementia still does not feature in the 'Services for the Elderly' business plans of the Department of Health and Children.

Irish people availing of health services either receive this free of charge through a universal medical coverage system or medical card system (26% of people aged 18 and over) or they have private health insurance (46% of 18 year old and over). A further 2% have

access to both public and private health care (ESRI, 2001)[xviii]. Entitlement to a medical card is means-tested with community welfare officers carry out these assessments. In 2001, all people aged 70 years and over were given automatic entitlement to a medical card, making primary health care free for everyone in this age group (free services included in this scheme are GP services, prescription medication with some exceptions, in-patient public hospital services, out-patient services, dental, optical and aural services and medical appliances). However, in 2008 (Budget 2009) universal access to the over-70s medical card was removed. Means-testing was reintroduced from January 2009, although the income threshold for entitlement is higher than for those under 70. Interestingly in Ireland people with medical cards are not entitled to free access to social care services (e.g. home help services) despite their receiving medical services for free, as there is no legislative entitlement to social care.

3.11.1 Community care

Community care can be defined as: "[an] approach to care that includes a range of services designed to keep people well, from promotion of health and screening for disease to assessment, diagnosis, treatment and rehabilitation as well as personal social services. The services provide first-level contact that is fully accessible by self-referral and have a strong emphasis on working with communities and individuals to improve their health and social well-being" (Department of Health and Children, 2001a: 15). The ideal, as promoted by the Department of Health and Children, in their Primary Care Health Strategy (2001b), is for community care to comprise of primary interdisciplinary care teams. Services included in these teams are: General Practitioners (GPs), Public Health Nurses (PHNs), Health Care Assistants, Home Helps, Physiotherapists, Occupational Therapists (OT) and Social Workers. Wider networks of auxiliary

[xviii] This indicates that over a quarter of the adult population are without either a card or private cover. These figures are based on a survey module on health, which was included in the Quarterly National Household Survey in the third quarter of 2001. Those who are not eligible for the medical card scheme are entitled to free hospital services (which are subject to an annual maximum charge of €400) but must pay for their primary health care (GP services).

professionals provide services to groups of these core primary care teams. These networks include Chiropodists, Community Welfare Officers, Community Pharmacists, Dentists, Dieticians, Psychologists and Speech and Language Therapists. Primary Care Teams (PCTs) are gradually being rolled out nationally albeit very slowly: in 2008 there were 104 primary care teams in operation. The HSE hopes to increase this to 210 PCTs in 2009 (HSE, 2008: 15).

Specialist care teams are also based in the community. These are teams specifically for palliative care, mental health, child care, disability (intellectual and physical/sensory), special client groups (for example traveller interests, homeless people) and community services for older people. In this study all respondents were accessing care through older people's services, as there are no specialised dementia care teams in the community. A possible reason for this is that specialist dementia care tends to be more expensive (Marshall, 1999: 94). Under the present system the difficultly for people living with dementia is that they span three specialist care continuums (disability services, mental health services and older peoples' services). This creates an issue for assessment. It also creates budgetary concerns, as each specialist service is run within its own budget. As a result, boundaries become blurred between policies for dementia that are aged-care related and those that are mental-health related (Marshall, 1999: 90).

3.11.2 Co-ordination and delivery of community care

The only dementia-specific community-based services available in Ireland are those provided by the Alzheimer's Society of Ireland (ASI). This causes difficulties around the coordination of services, as the Health Services Executive (HSE) does not directly manage services for people living with dementia. Generally, money is set aside by the HSE for the provision of services but they are managed by other entities, such as the ASI[xix].

[xix] The ASI is a national voluntary organisation. Established in 1982, it is a major dementia-specific service provider in Ireland with over 300 volunteers, 740 full-time and part-time staff and 3,000 members. Their mission statement is to work with those affected by Alzheimer's disease/dementia to maximise quality of life.

3.11.3 Secondary care services

Specialised older people's medicine is relatively new in Ireland. The first consultant geriatrician was appointed in 1969, although in the last fifteen years the number of geriatric consultants has tripled (O'Neill and O'Keefe, 2003: 1283). All hospitals in Ireland have a Department for Age-Related Care or Medicine for the Elderly, led by one or more hospital consultants or Geriatricians. In 2005, there were 45 filled geriatric consultant posts, with a further 12 vacant but approved posts (HSE, 2005). Age-related care teams[xx] usually comprise of two consultants, one senior registrar, two interns, clinical nurse managers and a specialist nurse trained in domiciliary assessment, stroke and falls. The team also consists of a physiotherapist, an occupational therapist and a speech therapist. Social work and clinical nutrition services are typically offered on a part-time basis. Some, but not all, hospitals have an Old Age Psychiatry team. In 2005 there were 20 old age psychiatrists in Ireland with one further post approved but vacant (HSE, 2005). Other secondary care services for older people include Day-hospitals and Outpatient Clinics. The Day-hospital is used by people who require at least two or more medical and/or rehabilitation treatments. Referral to the Day-hospital is made either by staff at the Outpatients clinic or from In-patients. An Outpatients clinic is attended for assessment, follow-up care and/or continuing management of care and is appointment based.

Age-related secondary care services also include memory clinics. These are a relatively recent addition to age-related health care settings. There are currently five memory clinics in Ireland, providing a referral-led service. People are usually referred to a memory clinic if there are questions surrounding a cognitive-related diagnosis. Of the respondents in this study, three had attended a national memory clinic.

[xx] The example given here is the Age Related care team in which all respondents in this study were linked to. The precise composition of care teams varies from hospital to hospital.

3.12 Policy Review

The establishment of the Health Service Executive (HSE) in 2005 was a move towards restructuring the Irish health system after the old health board system was abolished. It brought the health service under a national and unified structure, running under three directorates, namely; the National Hospitals Office; Primary, Community and Continuing Care (PCCC) and the Population Health Directorate. Under this new system four regional offices (ROs) were established (Western, Southern Dublin-Mid-Leinster and Dublin North-East). The delivery of primary and community care is the responsibility of 32 Local Health Offices (LHOs).

(Formal) community care for older people has no real historical basis in Ireland due to the high dependency on family members and informal networks to care for older people who require assistance. Although families have traditionally provided the majority of care for older persons (Convery, 2001: 83-85), they are not legally obliged to do so. This places a moral obligation on families to provide care, partly because there is no legislative requirement for the State to do so. Indeed the details of family members' financial means are considered in the provision of some services for older persons (Convery, 2001: 82), which constitutes further evidence of a familialistic model of care. The familialistic paradigm of long-term care as outlined by Timonen (2005: 33) occurs when families and individuals are for the most part responsible for financing and/or providing long-term care. Within this model, outside provision towards the cost of care is limited and means-tested, and there can be a stigma attached to service use, resulting in outside provision being seen as a last resort. Elements of the familialistic model are also evident in many other European countries, such as the Mediterranean countries. Other models of care outlined by Timonen (2005: 33) include:

- The statist model of long-term care: the State takes extensive responsibility for the financing and provision of care. The family's responsibility is voluntary and secondary to that of the

State. "Formal long-term care is seen as a right" (e.g. Sweden).

- The 'state pays, others provide' paradigm of long-term care occurs when there is a wide range of providers delivering care services, although the State assumes a great deal of responsibility for meeting the cost of care (means-testing plays a smaller role). However, State programmes and payments do not generally cover the cost of care in full, and private resources and social assistance is still often required (e.g. France and Germany).

It has been argued that community care services in Ireland are underdeveloped and poorly co-coordinated (Timonen, Convery and Cahill, 2006: 457). The earliest provision of public care for older persons focused on institutional and means-tested (residual) care, as help and support in the home and the community were assumed to always be provided by kin and neighbourhood networks (Timonen, Doyle and Prendergast, 2006: 37). The delivery of public health, community and home care supports in Ireland is the responsibility of the Health Service Executive (HSE), but in many countries health and social care services are divided and have separate budgets in terms of professional and organisational boundaries. This is not the case in Ireland where the same budget supports both sets of services. This can work well for those requiring acute care but is less helpful for people with chronic or progressive illnesses (Marshall, 1999: 93). This is further exacerbated in Ireland, as each Local Health Office controls health and social care within physical and budgetary boundaries. There is no proper legal framework for the delivery of community care and this lack of legislation also extends to needs assessment as there is no legislative provision for assessment of need of older people living in their own homes (Mangan, 2006: 358).

In 1990 the State recognised the role of informal caregivers with the introduction of the Carer's Allowance. This welfare payment is means-tested and at the time of writing was €232 a week. Other entitlements for caregivers include the respite care grant, free

household benefit, free television license, travel pass, and telephone rental. Other types of payments for caregivers include Carer's Benefit and half-rate Carer's Allowance. It is important to note that people are only entitled to one social welfare payment (other than the children's allowance) and people who are in receipt of a State Pension are not eligible for a Carer's Allowance. Estimating the number of carers for older people is difficult because of this and is further complicated by the fact that census information on the number of care-givers is not broken down by the age of the care recipient e.g. those providing care to older persons or those providing care to people under 65 years (Timonen, Doyle and Prendergast, 2006: 35).

The co-ordination of services faces another challenge arising from the historical development of service provision in Ireland. The development of formal care services was strongly influenced the Catholic Church (Timonen, Doyle and Prendergast, 2006: 35). This fostered a culture of voluntary or non-profit sector care provision. Successive Irish governments have perpetuated this trend by continuing to fund voluntary/non-profit organisations to provide formal care. More recently, private organisations have entered the home care market and this area is expanding with the introduction of home care support packages[xxi]. People are now buying in private services with public funds and thereby moving towards a system of 'State Pays, Others Provide' as outlined by Timonen (2005) above. These grants are most often referred to as Home Care Packages. Ideally, these packages are tailored to individuals' needs, based on a full assessment. There are no dementia-specific home care packages and the majority of recipients receive them on discharge from acute care, as current packages are aimed towards people with extensive care needs and are seen to serve the purpose of freeing hospital beds (Timonen, Doyle and Prendergast, 2006).

[xxi] Eligibility for home care support packages is means-tested. The scheme is still in its infancy and is not a nationwide service. Eligibility is also based on functional need where the person requires medium to high care support. There is no standard assessment for the packages and in the majority of cases the PHN carries out the assessment.

Two seminal Irish policy reports on older people are the Care for the Aged Report (1968) and the Years Ahead Report (1988). In 1968, for the first time, it was recommended that public policy should promote the maintenance of older people in dignity and independence in their own homes. Since the publication of these reports, this policy directive, regarding the maintenance of older people as independently as possible in the community, has been reiterated in many government reports and other policy documents (see An Action Plan for Dementia, 1999; Review of the Years Ahead Report, 1997; Shaping a Healthier Future, 1994). However, there is still a disparity between the funding of community and home-based care and long-term institutional care. The Programme for Government 2007-2012 made a commitment to develop a Positive Ageing Strategy, replacing the 'The Years Ahead' report which is now 20 years old and remains poorly implemented in many respects.

All groups involved in older peoples' care in Ireland support a policy of enabling older people to remain living in their homes (Mangan, 2006: 354). This is also the expressed preferences of older people themselves (Garavan, Winder and McGee, 2001). Despite this, the overall spending on community care for older people is low and successive government directives advocating the need for community-based care have not been matched by government spending. In 2006 it was estimated that 0.19% of GDP was spent on home care, while 0.43% of GDP was spent on institutional care (O'Shea, 2006: 11). The only legislation passed in the last few years relating to the long-term care of older people involved the provision of nursing home subventions (Mangan, 2006: 354).

In comparison to other EU countries Ireland has a relative young population and has not yet experienced the effect of the ageing of the baby boom generation to the same extent (which in Ireland's case is the cohort born in the 1970s). It is important and I would argue imperative to implement policies now for the future. However, it is reasonable to assume that Irish policy-makers are not at a critical

juncture in relation to policy responses to population ageing to the same extent as other countries.

3.12.1 Dementia-specific policy and services

In comparison to other illnesses, such as cancer and cardio-vascular disease which also affect large groups in society, dementia has received little policy attention. Where policy does exist it is mostly encompassed in larger generic policies and statements on ageing (NESF, 2006: 88). In 1988 the Years Ahead Report outlined a number of recommendations for the care of older people living with dementia. A difficulty with policy blueprints like this is that there is no guarantee that their recommendations will be implemented (O'Shea, 2006: 14) and many of the recommendations from The Years Ahead Report have never been put into practice.

Some of these recommendations include the introduction of screening programmes in the community to allow GPs and PHNs to identify people with the early signs of dementia. The report also calls for an expansion of Day care and Day-hospital facilities for people living with dementia. The report recommends that under the supervision of a senior PHN a panel of people should be established who are willing and able to provide care to those living with dementia. The Years Ahead also called for the provision of sufficient places in 'welfare homes' to be made available to people living with dementia who can no longer remain at home, with 'high support hostels' for those in the advanced stages of the illness. The provision of residential accommodation provided by the then health boards was seen as a matter of urgency. Another issue, which the authors of the report felt was urgent at the time, was the appointment of Old Age Psychiatrists in Dublin and Cork. Interestingly, whilst most of these recommendations have not been implemented, the recommendation relating to new appointments in the area of geriatric medicine and old age psychiatry have been operationalised (see Chapter Seven, section 7.2.3).

The most recent and extensive document pertaining to dementia-specific policies and services in Ireland is 'An Action Plan for Dementia' which was published in 1999. This plan examined best practice in dementia care and outlined 33 recommendations for the development of services. However, very few of these have been implemented despite a general acceptance of these recommendations in the 2001 Health Strategy (Department of Health and Children, 2001). The plan outlined a number of key policy areas: (i) development of a case management provision of care, (ii) increased public awareness about dementia to create a socio-cultural and political environment in which these policies can be delivered, (iii) an increase in early diagnosis through the training of front-line staff, (iv) creation of small-scale dementia-specific residential units, (v) development of a Dementia Services Information and Development Centre[xxii] (DSIDC) to disseminate and promote best practice in dementia care, (vi) development of appropriate psychosocial interventions to work hand-in-hand with neurological and medical interventions (with the promotion of multi-disciplinary teams) and (vi) the expansion of both community-based services (Day care and allied health professionals) and hospital care (Day-hospitals and the expansion of Old Age Psychiatry).

In accordance with the traditional model of care in Ireland which largely depends on families, informal carers and voluntary organisations, the main formal service provider of dementia-specific services is the Alzheimer's society of Ireland (ASI). It runs a home support service that provides home care to approximately 2,000 people living with dementia. The ASI run a number of dementia-specific Day Centres and in one centre they provide overnight respite care for their clients. In 2001, the ASI began piloting a dementia Care and Case Manager Programme in one area of south Dublin. However, this service has not been rolled out nationally. In the last two years the ASI received funding from the Citizens' Advice

[xxii] The DSIDC was established in the same year the Action Plan was written, in 1998. It is a national Centre for best practice in dementia care in Ireland. It provides information, training and education services to health service professionals working in the area.

Board for an Advocacy Officer specifically working with persons with dementia. This service is up and running on a pilot basis in north Dublin. The ASI has also purchased a small hotel in the west of Ireland which they are turning into a respite or holiday centre. The design of the centre will accommodate couples wishing to travel and stay together and the centre will be in easy access to the local town and other amenities. This is a change from the traditional provision of respite beds for people living with dementia in more hospital like settings. The ASI also runs a number of clubs for people living with dementia and their families, friends and carers. These are social gatherings held for half a day once a week. Clubs also plan activities and organise outings. However, these have not been rolled out at a national level. The ASI has widened their focus to include the needs of both the person with dementia and their caregivers. However, the development of services specifically for those in the early stages of dementia is still in its infancy. Although innovative projects focusing on services for people living with dementia have been established on a pilot-basis they are not yet feeding in to mainstream care. Kümper et al (2005: 1200) outline similar findings from their analysis of the English and Dutch dementia care services, where they report shortcomings in mainstream services.

3.12.2 Other systems of dementia care

Processes that shape care pathways and care concepts exist within historical contexts of health and social care systems, for example organisation and service patterns, balances of power and financial frameworks (Kümper et al, 2005: 1201-1202). Therefore, comparing health and social care system across countries should be prefaced by recognition of the significance of contextual differences. Similarly to Kümpers et al (2005: 1200) this thesis rejects the suggestion that lessons from one country or system have automatic application to another. Systems of care are affected by and reinforce cultural and public values, dominant political ideologies and history, and for these reasons are not easily 'transplanted'.

The OECD (2004: 20), in a comparative analysis of dementia care across nine countries (Australia, Canada, England and Wales, France, Germany, Japan, Spain, Sweden and the United States), found a number of universally accepted policy principles[xxiii]. These principles were:

- for the person to remain at home for as long as possible
- to support caregivers to achieve this
- persons with dementia need as much control over their care as possible, but recognise limitations due to cognitive impairment
- services should be co-ordinated at local level where possible
- institutional care should be as home-like as possible
- service provision should equate with need
- encourage early diagnosis

Kümper et al (2005: 1208) also found commonalities across recommended dementia care standards in England and the Netherlands, namely; early identification, diagnosis, needs assessment, comprehensive case management, the provision of home-based care and dementia-specific training and knowledge for care staff at all stages of the dementia process. It has already been shown that similar standards are promoted in Ireland (An Action Plan for Dementia, O'Shea and O'Reilly, 1999).

There are differences in the implementation of standards as well as country/cultural differences. Kümper et al (2005: 1208) found major divergences between standards and practice. For example, common barriers to the implementation of standards in England and the Netherlands included: the medical professional culture; traditional care models; cost containment and difficulties (re)integrating differentiated and specialised service systems. The system in England had a strong focus on independence for people living with dementia, prioritising non-institutional community care and widespread negative attitudes towards institutional provision. In the Netherlands, traditionally, there were much higher levels of institutional care, with a focus on 'caring for' (a paternalistic

[xxiii] Taken from Marshall (1999) and Riggs (2001)

approach) rather than empowering or enabling the person to live as independently as possible. There is also a strong focus on carers' needs in the Netherlands. Kümper et al (2005: 1213) state that the approach taken in the Netherlands is a better fit for people who are in the later stages of dementia. In Ireland, the financing of care for older people is skewed towards long-term institutional care which runs counter to the aspirations outlined in all policy documents since 1968 where priority is to assist older people to live as independently as possible in their own homes for as long as possible. Similarly to other countries where implementation of policy is poor, the recommendations of An Action Plan for Dementia (O'Shea and O'Reilly, 1999) have not yet been implemented despite continuous calls for this (Health Strategy, 2001; Working Group on Elder Abuse, 2002). This suggests that while there are aspirations regarding standards of care for dementia in Ireland, their implementation is more problematic.

3.13 Chapter Summary

This chapter examined conceptual understandings of dementia, to the literature on the lived experience and the broader socio-political structures of the Irish health and social care system and policy pertaining to the area of dementia care services and practice.

The first part of this chapter outlined the experience of dementia as a cognitive disability, framed within a Personhood or person-centred approach. It explained how understandings of dementia have moved beyond the medical model to psychosocial models, incorporating Personhood and sociological explanations of the illness, social disability models and the citizenship model. It highlighted the importance of personhood for placing the person with dementia at the centre of the practice and research enquiry but concluded that this approach is strengthened by incorporating citizenship as it gives the person living with dementia further entitlements as well as obligations. As Thompson and Thompson (2001: 66) state, "if we are to regard an older person as someone who has the right to as

'normal' a life as possible, the focus switches from care and dependency to a much more positive ethos of rights, participation, empowerment and interdependency".

The literature review on the lived experience of dementia shows how under-developed this area of enquiry is in Ireland. Studies from other countries reveal how both internal and external factors affect the experience of living with dementia, all of which contribute to the personal experience of dementia. For example, awareness, sense of identity, coping strategies and management techniques to address dementia are internal yet are also affected by external factors such as stigma, participation, changing roles and a person's relationship with others.

The literature review also illustrates the complexities of issues relating to dementia, one of which, awareness, and was examined in great detail. No one common definition of awareness exists across disciplines and as such it means different things to different people. A gold standard also does not exist on how to measure awareness. However, work by John Killick (2001) has shown how we can gain much from applying alternative methods through poetry to gain insight into people's understanding of the changes they experience as a result of living with dementia.

The literature review also highlights similarities between a Personhood approach and the work of Steve Sabat and the social constructionist approach to dementia where the self (personae) 3 is linked to how we interact and engage with other people. As a result, with the onset of dementia, these interactions and engagement can change thus affecting the person's sense of self.

The chapter finished with a review of the Irish health and social care system, outlining its unique mix of public and private service provision. Broad characteristics of this system were identified as:

(i) low spending on community care, in comparison to institutional care

(ii) dependence on a familiaristic/informal model of care (promoting a paternalistic model of care)

(iii) legislatory underpinning community based medical care but no legal entitlement of social care

(iv) aspirations regarding standards of care but implementation is more problematic.

Interestingly this final characteristic was a common finding when other countries were examined in how they address dementia (OECD, 2004). A divergence of standards and practices across countries is evident despite the existence of many similar principles.

Together, these reviews of literature and the Irish health and social care system provide the 'context' or the starting point for my own enquiry into the lived experience of dementia. I'll now go on to outlined the research questions that I derived from this review and the methods I used to collect the data to answer these questions.

CHAPTER FOUR: RESEARCH QUESTIONS AND METHODS

4.1 Introduction

This chapter outlines and justifies the methodological design of the study. An Interpretive Phenomenological Analytical (IPA) approach using qualitative methods was used, where in-depth interviews were carried out with 17 people living with dementia (phase one of data collection), 13 care-partners (phase two of data collection) and six key policy experts (phase three of data collection). This chapter also outlines the key research questions and explains how they link back to the overall objectives, development and methods of the study.

When the design of this study was being conceptualised, a number of ethical issues were identified which needed consideration before I entered the field. These issues are examined in this chapter under the headings: (i) the inclusion of people living with dementia in the research process, (ii) the role of the researcher and reflexivity, (iii) conducting sensitive research, (iv) varying levels of awareness of diagnosis amongst respondents and (v) capacity to consent. Broader ethical principles, such as autonomy, justice, beneficence, confidentiality and voluntary participation as well as the processes involved in gaining ethical approval are discussed in this chapter.

This chapter also outlines the procedures used in data collection. The first step was to recruit a sample. All respondents were recruited through the same service provider, an Age-Related Outpatients clinic at a large Dublin-based hospital. Interviews were semi-structured adhering to an IPA approach, however a number of structured questions were asked of respondents with the view of comparing the quantitative data that emerged with the qualitative data (see section 4.6.6 'types of data collected' for further information and discussion on this issue). The chapter also considers the analytical approach that was taken to data gathered from respondents living with dementia, Interpretive Phenomenological

Analysis (IPA). The final part of this chapter describes the limitations of the research methods.

4.2 Research Questions

The principal aim of this research was to shed light on the lived experience of dementia. Another central aim was to explore the experiences of people with early-stage dementia in seeking and using health and social care services, therefore placing the lived experience within a broader socioeconomic and cultural context. I also wanted to develop appropriate research methods to facilitate the inclusion of people living with dementia in the research process[xxiv]. The overall aims were broken down into a number of specific research questions. These questions were further developed through reflection on the theoretical and conceptual framework (social constructionism, person-centredness and citizenships models); as well as through a review of the literature (as outlined in Chapter Three). The research questions are as follows:

- What does it mean to have dementia?

The rationale for focusing on this question comes from Clare (2002a: 139) who asserts that it is only by improving our understanding of the lived experience of dementia that appropriate interventions and services can be developed that effectively meet need. Drawing on person-centred approaches, the person living with dementia is at the centre of the research enquiry. Looking also at how people with disabilities interact with socially constructed environments. This is also linked to the second research question, namely:

- What are the social implications of having dementia?

Social constructionist approaches, as outlined in Chapter Three, can help us to understand how the social world influences the experience of dementia. Moving beyond people's medical needs, this question addresses how respondents interacted with the world around them and how this changed over time. It examines how other peoples' reactions and interactions with them affected their experience of the

[xxiv] A methodology is a way of thinking about and studying (social) reality (Strauss and Corbin, 1998: 3). It is concerned with the techniques or methods applied in the process of scientific enquiry, that is, in answering the research questions.

dementia. The social implications of having dementia are also linked to the broader structures of service provision and policies, hence the third major question that this thesis addresses is:

- What are the current service provisions in Ireland for people living with dementia?

This question therefore examines the broader 'macro' context by investigating the larger policy and services framework in which people experience the illness. From the investigation of the models and approaches to dementia taken and presented in Chapter Three, it was shown that in the last 40 years there has been a move away from the traditional approach of institutional care. This is partly due to the development of the social disability movement with new thinking on the promotion of independence. This has been the case for intellectual disability and for old-age services. Can we say the same for those living with dementia? One of the aims of this thesis is therefore to investigate this. The thesis also sought to gain an insight into how respondents used these services and what their thoughts were on them, hence the fourth central question:

- How do people living with dementia access services and other interventions?

The OECD (2004) outline as the universally accepted policy principles that services should be co-ordinated at local level where possible and that service provision should be commensurate with need. This question looks specifically at how people were referred to services and what referral pathways existed for them.

- What are the social policy implications of this user-led investigation?

This question considers current policies and places respondents' experiences within the current care system in Ireland. It also considers data collected from policy experts, highlighting the policy implications of the findings and discussion chapters. This evokes elements of the citizenship model by examining whether the status and treatment of people living with dementia is disempowering and whether they feel marginalised by current policy and practices. To combat this marginalization we need to be inclusive of their views

and listen to their stories, hence the final question addressed in this work was:

- What is the most appropriate way to include people living with dementia in the research process?

Froggart (1988:132) states that it is only through listening to people living with dementia that we can begin to grasp what their experiences are. A person-centred approach places the person with dementia at the centre of the research enquiry. In recent years, there has been an increase in the number of original pieces of research, as shown in Chapter Three, which include people living with dementia. As a result, best practice in dementia research is now developing. My thesis, it is hoped, will add to the existing body of knowledge in this regard.

4.3 Terminology

All names in this thesis have been changed to protect the identity of respondents and of their care-partners. Each respondent was given a pseudonym and a code number (e.g. 030). These code numbers are ordered in relation to when interviews were carried, 004-Mrs Beattie was the first respondent included in the final sample and 041-Mrs Martin was the last. Policy experts are referred to by their job titles rather than by their name. All quotations from policy experts presented in this thesis have been seen and approved by them.

I became aware after talking with practitioners and the referring service provider that many people living with dementia are never told their formal diagnosis; often they are told in softer terms that they have a memory problem. Another consideration, as outlined in the literature review, was that sometimes people cover-up or deny the presence of an impairment. It is common too, that people living with dementia can be reluctant to use words like dementia or Alzheimer's disease, preferring more descriptive terms to refer to their cognitive disability (Langdon, Eagle and Warner, 2007: 993). Sensitivity to these situations was therefore required. As a result, during each interview, dementia was referred to as respondents' memory problem. The

words 'dementia' or 'Alzheimer's disease' were not used unless and until the respondent used these terms him/herself.

The key supporters of respondents living with dementia interviewed for this study are referred throughout the thesis as care-partners. When carrying out the analysis I reflected on the use of the word carer, a term often employed to describe a person performing care tasks for another. Family members interviewed for this thesis were not care-givers in this traditional sense, as the majority of respondents in this study were very independent and did not require much assistance with activities of daily living. The term care-partner was taken from Bryden (2005), who talks about herself and her husband being each other's care-partners through their journey into dementia. Emotionally, psychologically and physically they support each other. In this way they are approaching the illness together, recognising that it has an effect on each of them, not just on the person with the illness or solely on the person who has to provide care, reflecting a relationship-centred approach. I felt that 'care-partner' was an appropriate way to describe the relationship respondents had with their family members who participated in the research.

4.4 Methodological Design

A careful approach to designing the study was required since the research involved people living with dementia and therefore an approach was needed which limited distress and encouraged meaningful participation. I was somewhat influenced by my previous experience as a researcher on a longitudinal study which included people living with dementia. Another influence was my cognisance of the challenges some people living with dementia have in relation to perception, understanding, memory and motivation. Before deciding on the procedures and methods to be used I needed to reflect on these issues and think about what was the most appropriate way to collect the data, considering that there are effects of dementia that could influence how the study was designed

and administered. These effects could have extensive ethical and methodological implications for the research. For example, if the person had communication difficulties, e.g. aphasia[xxv] and dysgraphia[xxvi], these could influence the way people's experiences were communicated. These were combined psychosocial reactions such as unwillingness to talk about their experiences. If respondents had recently received a diagnosis they may be anxious or stressed. The data collection methods and methodological tools used needed to acknowledge the effect of both the biological symptoms and the psychosocial impact of living with dementia. I also needed to be sensitive to the possible vulnerability of respondents. Considering this and looking at other similar research, I concluded that qualitative in-depth interviewing would be the most appropriate approach to take.

4.4.1 Methodological Framework

There are three data sources in this study namely (i) people living with dementia (ii) their care-partners and (iii) policy experts. Qualitative in-depth semi-structured interviews were used to collect data from each of these three respondent groups. However, interviews with policy makers were closer to structured interviews and interviews with respondents more unstructured, as questions were open-ended and wording and order of questions were adapted to each respondent: this approach is illustrated in Appendix G, which contains two full transcripts of interviews with two respondents. Following Bryman's (2001: 314) description of semi-structured interviews I had a list of questions or topics to be covered but the respondent had "a great deal of leeway in how to reply" and I also allowed the respondents to introduce new avenues and probed into those as they emerged. Thematic analysis was used with policy expert interviews, while Interpretive Phenomenological Analysis (IPA) was applied to data collected from respondents living with dementia.

[xxv] This is impaired language affecting the production or comprehension of speech and the ability to read and write.
[xxvi] Dysgraphia is difficulty expressing thought.

As the central crux of this enquiry is to examine the lived experience of dementia and following a review of the literature on including people living with dementia in research, I noted the prevalence of phenomenological approaches. For instance, the review of psychosocial research including people living with dementia by Steeman et al (2006) shows that of the 28 studies reviewed all were qualitative and the majority (N=10) applied a phenomenological approach. I had initially considered a grounded theory approach for this thesis but because the main aspect of the enquiry was examining the meaning of the lived experience, phenomenology presented itself as more appropriate to gathering and analysing data from people living with dementia. This thesis follows Interpretive Phenomenological Analysis which has its origins in phenomenology and symbolic interactionism (Brocki and Weardon, 2006: 87). The following section describes IPA and elements of a phenomenology approach in greater depth.

Phenomenological is based on principles found within Philosophy, Sociology and Psychology. It concentrates on in-depth investigations typically involving long unstructured or semi-structured interviews with small numbers of respondents. The conceptual framework of this thesis is also heavily reliant on phenomenology as it is linked to person-centred care and approaches to research that seek to involve the research participants to the maximal degree. As Brooker (2004: 217) states, an element of person-centred care is looking at the world from the perspective of the person with dementia, she states it is part of the phenomenological school of psychology.

One of the reasons a phenomenological approach was deemed suitable in the main was because data analysis within this method of enquiry follows a reductionist approach, where all possible meanings of statements and themes are investigated, resulting in a general description of the experience or the 'essence' of the experience (Creswell, 1998: 65), in this case the lived experience. IPA itself can be described as having three broad elements; an epistemological position; a set of guidelines for conducting research and describes a

corpus of empirical research (Smith, 2004: 40). Using Interpretive Phenomenological Analysis (IPA) is to first 'give voice' to respondents concerns (describing) and to second 'make sense' (interpretive) of these concerns (Larkin, Watts and Clifton, 2006: 102).

Phenomenology argues that there is an objective world but it is experienced through consciousness not through the senses (Sarantakos, 2005: 44). It views the world as being created by people, and as such it focuses on 'peeling back' the layers and thereby getting to the essence of the person's perception of reality, where the person's reality (consisting of their experiences, attitudes, feelings and thoughts) is "treated as pure 'phenomena' and the only absolute data from where to begin" (Groenewald, 2004: 4). Relating this to people living with dementia highlights how their reality can be very different to other peoples' perceptions of the lived experience of dementia.

An IPA approach places an onus on the researcher to be reflective, examining their own prejudgements and their own experiences[xxvii]. IPA recognises that the researcher's judgement is inevitably to some extent influenced by their own background (Benner, 1994). Creswell (1998: 52) states that the phenomenological researcher must rely on intuition, imagination and universal structures to gain a full picture of the experience under investigation. In this way accurate and reflective outcomes can be achieved. Kvale (1996: 54) argues that there is not a complete absence of presuppositions in phenomenological reduction but rather a critical analysis of one's own presuppositions. In this way the role of the researcher is considered (see section 4.5.2 of this chapter for further discussion on this issue) and an acknowledgement that the qualitative researcher can have an impact on outcomes is made.

4.4.2 Qualitative methods

Since this study is exploratory (it is the first study of this kind in the Irish context) and descriptive (it seeks to describe rather than provide

[xxvii] This is often referred to as bracketing or epoche.

causal analysis), qualitative methods were the preferred research approach. Qualitative research is fundamentally about quality rather quantity. Qualitative methodologies do not demand large sample sizes but there is an expectation of 'depth' in how the data is collected and in how it is analysed. This demands rigour and thoroughness. Qualitative research makes no claims to be representative of the population it is studying. However, it is pragmatic, interpretive and grounded in the lived experiences of people and is orientated to understanding these experiences (Bassett, 2004: 4). It can also make people feel that they have a voice and that other people are listening to their concerns and are interested in their opinions and experiences (Gibson et al, 2004: 423). This is particularly important in social research on dementia as we have seen how it is only recently that people with the illness have actively been involved as research informants.

Qualitative methodology is inductive, yielding and developing theory rather than testing theory. As Creswell (1998: 15) states, it is: "a process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyses words, reports detailed views of informants and conducts the study in a natural setting". In this way a picture of the phenomenon or experience under study is developed.

Qualitative research is advocated in investigations on the subjective or lived experience of dementia as it involves complex conditions and situations (Harris, 2002). It allows for the research to be underpinned by a philosophy of what Mays and Pope (2000: 51) call "subtle realism", where the method attempts to describe and represent that reality rather than try to obtain an absolute truth. This is pertinent for this thesis, as attempts to uncover the real experience of people living with dementia should not depend on proxy reporting.
From the outset a goal of this study was to allow participants to actively engage in the research process. A qualitative approach facilitated this, as it examines how respondents understood and

interpreted their social realities (Bryman, 1988). I wanted respondents to feel they were valued as experts in their field. I hoped too that their involvement made them feel like active participants in the research process. Pilot interviews with a person living with dementia and three people with 'mild cognitive impairment' helped to identify broad thematic areas to be covered in data collection. They also provided some confirmation that topics/themes I had identified through the initial literature review were relevant to them. The pilot interviews also helped me to learn how to approach respondents and to develop ways in which I could adapt to different situations and to confirm.

Qualitative methods allow for greater flexibility in data collection. Other sources of data can be invaluable as well, such as body language and facial expressions[xxviii]. These were noted in fieldnotes and used to jog my memory and set interviews in context during analysis and hence assisted with reflexivity. The social and physical environments in which respondents lived were also noted extensively in the research fieldnotes and were a valuable source of contextual data. Having a flexible research design allowed me to adapt to each individual respondents. As each person experiences the illness differently, I often had to change my approach to facilitate individuals; this is discussed further in the following section on interviewing.

4.4.3 In-depth interviewing

In-depth semi-structured interviews, unlike interviews in quantitative research, are dynamic and flexible (Taylor and Bogdan, 1998: 88). Applying an Interpretative Phenomenological Analytical approach means questions are more open-ended, person-centred and non-directive. Qualitative methods allow interviews to be conducted in different ways with different respondents, adapting question format and question sequence to the characteristics and preferences of individuals. This was particularly appropriate in this study as no two

[xxviii] This is not an ethnographic study and interviews with respondents were deemed as sufficiently rich source of information for the research.

participants with dementia responded in the same way. In-depth interviewing is also about learning what questions to ask and how to ask these questions, rather than merely obtaining answers (Taylor and Bogdan, 1998: 88). In this way a broad to specific approach to questioning was implemented. For example, I began by asking 'can you tell me about your memory problem?' This broad question was followed by more specific questions on what type of things respondents forgot and how this made them feel. Specific questions were only asked if respondents had not addressed key aspects/areas when answering the broad initial question. In this way interview schedules were used as a guide. Questions were asked in a conversational way and were not necessarily asked in the sequence in which they are presented in Appendix C nor in the way they are worded in the interview schedules. I wanted to give respondents as much freedom to express their views in their own way; as Todres and Galvin (2005: 5) state, it gave them "maximum freedom in expressing the range, scope and boundaries of the complex experience". Appendix G contains two full transcripts of the first interview I had with Mrs Beattie (004) and Mr Murphy (030) and shows how the interview approach and adaptation of interview schedules were carried out in practice. The beginning of the interview with Mrs Beattie is more structured, following the interview schedule, but as the interview progresses Mrs Beattie begins to lead the interview more. In this way, the philosophy of person-centredness was applied to the research design and in researcher/respondent interactions.

Whilst flexibility in approach was maintained, I ensured that the same core topics (outlined in section 4.6.6) were explored with each of the respondents. It bears repeating that the interview schedules were used to guide me rather than as a structured approach to asking the questions. I outlined each theme under a specific question although they were not administered in this way. The literature review and pilot interviews that I conducted had led to the identification of a number of core areas that the interviews sought to cover in a flexible way, relating to the lived experience and respondent's health and social care experiences. Whereas quantitative interviewing is structured

and rigid, in-depth interviews can be adapted and moulded to suit each individual: it is a conversation between equals rather than a question-and-answer session (Taylor and Bogdan, 1998: 88).

A fundamental component of in-depth interviewing is that rapport and trust are established between the interviewer and the informant. Nicholson (2003: 144) argues that the processes involved in in-depth interviews can never be neutral, unbiased or objective. She states that the "interviewer and respondents are engaging or failing to engage with each other. As this process involves a mutual construction of the topics under discussion, both participants need to be reflexive". Rapport and trust were achieved through repeated contacts. People living with dementia took part in two face-to-face interviews that were scheduled one week apart. I also met participants at the hospital when referral for the study was made and in some cases where news of their memory loss problem had just been disclosed. As a result, I had at least three face-to-face contacts with respondents. I thought it would be useful to spend time with respondents prior to the first interview in order to build rapport and to break down any social barriers, as recommended by Proctor (2001: 374). Frequent contact reinforced my presence and gave respondents more opportunity to be at ease in my company. In addition, after recruitment, follow-up contact was made via telephone calls to participants and a letter and information sheet were sent to them after the initial meeting. Interviews were scheduled as quickly as possible after hospital appointments in an attempt to maintain continuity and familiarity.

A number of different approaches to data collection were therefore taken, involving the gathering of information from people living with dementia, their care-partners and policy experts. In adopting a relationship-centred approach, the views of three of the main stakeholder groups involved in the experience of dementia are represented. This approach recognises that different groups or stakeholders have their own vested interests. It has been noted in the literature that practitioners and researchers need to be more fully

aware of the family politics of dementia care, where the interests of all stakeholders compete with one another (Adams, 1998: 619).

4.5 Ethical Considerations for the Research Design

In undertaking this research I wanted to ensure rigor. Part of this and scientific research demands careful consideration of all ethical issues, particularly if I wanted people living with dementia to successfully be included in the research. These considerations needed to be addressed prior to designing the study, ensuring that they became embedded in the entire design. Other considerations centred around how to conduct research on sensitive topics, accommodating varying levels of awareness and respondents' ability or 'capacity' to participate. The following section examines the ethical considerations and includes some reflexive thoughts following data collection and analysis.

4.5.1 Including people living with dementia in research

Person-centredness plays a central role in this study as respondents living with dementia were the linchpin to achieving the research aims and objectives. This created many opportunities and benefits but also unique challenges. There is no gold standard for conducting research that includes people living with dementia but as Chapter Three outlined, much can be learned from other researchers who have involved people living with dementia in their work. The review of the literature on the lived experience of dementia was instrumental in the development of research methods to assist in the participation of people living with dementia in the research. It is recognised that finding out what people living with dementia want can be difficult. However, this does not mean it can not be done (Goldsmith, 2002: 161). Fundamentally, developing and implementing methodologies that successfully include people living with dementia should give the person an active voice. Close observation and discussion with people living with dementia shows that they can have insight into and awareness of what is happening to them and around them (Froggart, 1988: 132).

I previously worked as the Research Officer on the ENABLE[xxix] project, co-ordinating the fieldwork in Ireland. This European study sought out the views of people living with early-stage dementia. As a result of working on ENABLE I was convinced that people living with dementia could be accurate informants on their life experiences, provided that person-centredness was a core research motif. This conclusion was drawn as respondents in the ENABLE project engaged well in the research process, the information they gave was valuable and the study was largely respondent-led. This experience, however, raised issues about my own preconceptions: it was important that I was reflexive in my interactions with the respondents who participated in this study and in how I analysed the data, separating my experiences on the ENABLE project and my experiences with respondents involved in my thesis research.

Proctor's (2001: 374) study of four older women with dementia recognised the time-consuming nature of inclusive research. However, she states that "they [research participants] seemed pleased that what they spoke about was being taken seriously and their views were considered". Her study illustrates the benefits of qualitative inclusive research to those taking part, although it is not an intentionally therapeutic intervention. Nicolson (2003: 136) in a study examining the subjective experience of post natal depression puts forward the idea that the process of being interviewed represents an intervention in the everyday life of the person being interviewed. When I carried out interviews for this thesis it became apparent that respondents were receiving very few, if any, interventions and therefore engagement in the interview process could easily have been perceived as an intervention.

Consent is another central issue when including people living with dementia in research (see section 4.5.6 for further discussion on informed meaningful consent). Proxy consent in dementia research was standard up to the 1990s. Consent was usually given by family

[xxix] Enable (Enabling technologies for people with dementia) was an EU-funded project examining the role of assistive technologies for people with dementia and for their care-partners.

members for the person with dementia to take part. If we take a legal viewpoint, care-partners or family members can give consent on behalf of their care recipient only when power of attorney[xxx] exists. While proxy consent could have been used in this study it negates the role of respondents as active participants. After considering the literature and my own objectives for carrying out this research I decided that using proxies in this case would have run counter to the fundamental aims of the project, namely to (i) include people living with dementia in the research process and (ii) to develop methods for successfully achieving this. In circumstances where the possible participant was legally to lack capacity (which requires a medical assessment) and did not meet the inclusion criteria, he or she did not take part in this study. In most cases care-partners acted as secondary gatekeepers. However, it was important that respondents did not feel coerced or manipulated into taking part. This can sometimes occur if a carer, thinking they are acting in the best interests of the person with dementia, assumes incapacity and takes on the role of decision-maker in the other's life (Jacques, 1997). This 'benign paternalism' as the Law Reform Commission (2005: 26) states "treats adults who are deemed to lack capacity as similar to children in the sense of the parent deciding what is best for them because they know best" (The Law Reform Commission, 2005: 26). I was aware of this when obtaining consent and it was important that primarily consent was sought from the respondent and then from their care-partner (if they had one). In all cases both verbal and written consent was obtained from respondents.

4.5.2 Role of the researcher and reflexivity

To be reflexive and to apply the methods of IPA correctly, I needed to consider the role I would play in the whole process. In doing this, a a number of key areas emerged, namely: the differential power relationship between myself as the researcher and the respondents; researcher bias; my ability to bracket personal experiences and how

[xxx] Power of attorney allows another person to make decisions on behalf of the intellectually incapacitated person but only when this has been agreed by the person at a time before they become legally incapacitated (Wilcock, Romola and Bucks, 1999).

respondents viewed me. Gough (2003: 23) states that at the very least reflexivity is about the researcher making visible their individuality and how it affects the research process. In relation to the methodological theoretical approaches utilised in this thesis, Gough (2003: 25) states that "a phenomenological commitment (to reflexivity)...would prompt sustained self-reflection in order to reveal personal values and intersubjective experience relevant to the phenomenon in question".

I think it is true and fair to say that researchers enter the field striving to be unbiased[xxxi] and objective, yet life experiences unavoidably influence understandings and interpretations. Reflexivity is then an important tool for the researcher to use. This refers to the awareness of the researcher before, during and after data collection, of how their role and the role of the research process have "shaped the collected data, including the role of prior assumptions and experience, which can influence even the most avowedly inductive inquiries" (Mays and Pope, 2000: 51). At the time of interviews I was 27 years old, a student funded through a university to carry out this research. I did not have a disability and was not cognitively disabled. These characteristics shape my perspective of life and the world. A person can not separate these from their role as researcher, or from any interpretations of information given. Having worked previously on another dementia project, my expectations entering the field had already been influenced. I was aware that consideration of my own life experiences can impact on interpretations of the data, it can exclude conclusions that were initially drawn and it can bring attention back to respondents where possible meanings are considered from their perspective.

Finlay and Gough (2003: ix) state that reflexivity addresses the issue of subjectivity in research, changing it from problem to opportunity. It involves thoughtfulness, self-awareness, critical self-reflection and analysis of the dynamics between the researcher and the

[xxxi] Bias is the "the combination of various design, data, analysis and presentation factors that tend to produce research findings" (Ioannidis, 2005: 697).

respondents (Finlay and Gough, 2003: ix). "The researcher is a central figure who actively constructs the collection, selection and interpretation of data" (Finlay, 2003: 5). I followed Gough's (2003:23) outline of ways to apply reflexivity by;

(i) **Reflecting on my personal motivations** for choosing the topic of inquiry, as outlined in the first chapter. As well as my professional motivations, I had worked in the dementia social research field and felt that a gap existed in our current knowledge. Optimally I wanted the research to have some practical utility. It seemed feasible to then examine the 'micro' lived experienced in the context of a broader 'macro' (Irish health and social care) system.

(ii) **My choice of interview questions** was initially influenced by my motivations for carrying out the research i.e. the desire to understand the lived experience of dementia and the experience of people living with dementia within the Irish health and social care system. However, these questions and the additional focus on the social implications of dementia and care pathways were also influenced by a review of the literature and theoretical/conceptual frameworks developed by others. I was very interested in the social construction of dementia in relation to engagement and participation, which became a central theme of this thesis (see Chapter Six).

(iii) **My choice of interviewees** was largely and inevitably based on accessibility. It was difficult to identify a formal gatekeeper and initial attempts through the voluntary sector were not successful. I then approached hospitals and memory clinics as I thought that the chances of recruiting people who had recently been diagnosed would be higher at these sites. Once I gained consent from one hospital I decided that it would be conducive to a systematic approach if each respondent had received the same amount and type of care, therefore everyone was recruited from the same site.

(iv) **My expectations on what the research might yield.** These were largely based on my previous work on the ENABLE project, where my experiences were largely positive. However, I tried to bracket these and allow respondents and the data to tell their own story. Examples of this are given in the findings chapters.

Reflexivity applied in in-depth interviews is more than simply applying it during data collection. The interview is not just about collecting data on a tape for later analysis, it involves two people sharing a particular experience; as Nicolson (2003: 139) states, it involves bringing individual and shared consciousness into play. Being reflexive about an interview is remembering what it was like outside of listening to the tapes or reading over the transcripts. For instance when I think of an interview with Mrs Beattie (see Appendix G) I remember enjoying the conversation, she was very open and welcoming. She was also very aware of her diagnosis which avoided the challenge I faced when interviewing people who were not told or did not remember their diagnosis.

Having a week between the interviews gave me the opportunity to reflect on what the first interview was like and time to consider what approach I would take for the second interview, not just what data would need to be collected but how my interaction with the person could be improved. As stated above, reflexivity is about how you as a researcher and as a person engage with respondents. It is natural to care about them, some more than others (Nicholson, 2003: 138). For example, looking back over transcripts, responses to things respondent said were not always about data collection, at times it was an attempt to reassure the person. An example of this is from an interview with Mr Burns (017), where he became visibly upset when I asked him a question about his wife:

> *"Interviewer: Would you say you lean a lot on Vera? Respondent: Ah you do, she has her things to do and I'm taking that away from her you know (the respondent became visibly upset), more or less. Interview: But you'd*

do the same for her if she needed it? Respondent: Well that's the way.

A way of addressing bias was to ask respondents to clarify themes raised in the first interview during my second visit with them. Respondents were also asked to expand on these topics, thus assisting analysis and interpretation. While this did not negate the presence of bias, adopting an IPA approach went some way towards addressing this issue.

Another aspect which was considered was how respondents viewed me. Some saw me as a young girl, a curiosity: why would I want to work in this area and why was I interested in this topic? However, a positive outcome of this was that people were very willing to talk and disclose to me their private and personal experiences. I was seen as unthreatening and not seen as a representative of any formal institution. I was introduced to respondents through the hospital, in some ways this legitimised my study. This openness could also have been a result of the limited opportunity the respondents had had to talk about their experiences prior to the interviews I conducted. The loss of inhibitions which people can experience as a symptom of dementia may also have played a role in this.

4.5.3 Conducting sensitive research

Research can be defined as sensitive if topics that arise are private, stressful or sacred and where an emotional response is produced (McCosker, Barnard and Gerberm, 2001). Whether a topic is deemed sensitive is dependent on the context and cultural norms and values (McCosker, Barnard and Gerberm, 2001). McCosker, Barnard and Gerberm (2001) also state that conducting sensitive research means that procedures and processes need to be implemented that minimise the risk of negative psychological and emotional outcomes for participants, the needs of research participants are paramount. Carrying out research that hears the voice of people living with dementia is an extremely sensitive procedure. For this reason, it was essential that no harm would be inflicted on or experienced by

participants. Asking anybody about their life experiences is personal, even more so for people who have recently experienced significant changes and life events, such as receiving a diagnosis of dementia.

Another reason why studying dementia requires much sensitivity is that there is a general lack of knowledge and awareness about it. Dementia as a word and an illness can be hugely stigmatizing and as a result can be cloaked in dread. Society's attitude to any illness that has an effect on the mind is often negative. People do not want to be stigmatised and as discussed in Chapter Three (and subsequently in Chapter Six), they often implement coping mechanisms and systems to conceal dementia from others (Keady and Nolan, 1994). Of course this is not always the case, but it can be argued that ageism is rife in our society and this impedes open discussion of age-related illnesses including dementia which creates labels and the 'normal' treatment of people living with dementia is adversely affected. All of these factors make researching this area more challenging.

In a number of cases, one of which was referred to above, respondents became noticeably upset during interviews. In situations such as these, they were always given the option of discontinuing the interview. Yet no interviews were stopped because of this. I was sometimes unsure on a professional level what I should do when respondents became upset and in retrospect some training around this issue would have been beneficial for me and for respondents. On a personal level I think that talking about problems and indeed getting upset is not negative and as Kitwood argues, people living with dementia should be 'allowed' experience a wide range of different emotions. This personal belief influenced how I interacted with respondents as a result. Lee (1993: 107) also states, whether researchers or respondents realise or anticipate it, interviews can be a cathartic experience for participants. There is often a lack of opportunity for people living with dementia to talk about their experiences and taking part in the research could have given them the opportunity to do this. At times it was difficult to avoid certain

themes, despite the knowledge that they might cause some distress, for example discussing fears for the future. This affected my role as researcher, as I was not trained in counselling and felt a little out of my depth, yet at times I was in a position to offer reassurance and to point respondents in the direction of other sources of information and advice. Contact details for the Alzheimer's Society, Citizens' Information Centres, the Senior Citizens' Helpline and the Carers' Association were brought along to each interview and provided to the respondent if appropriate and requested.

4.5.4 Awareness of a diagnosis

Another consideration, already mentioned, and which had an effect on the design of the research study was the level of respondents' awareness of their diagnosis and the terms and terminology that would be used. This was not covert research and it was important that respondents knew and understood the aims and objectives of the study. As mentioned in an earlier section, when undertaking this research it was decided that the terms 'dementia' and 'Alzheimer's disease' would only be used once it was established that respondents were aware of their diagnosis and used these terms themselves. In six cases respondents had been told that they had dementia and in the remaining 11 cases they were told it was a deteriorating memory impairment. In some cases initial discussions with respondents' supporters (care-partners and other family members) and the referring service provider helped to ascertain appropriate terms that respondents would be comfortable with. In all cases the term 'memory problem' was used unless and until respondents referred to their memory and cognitive disability as dementia. Not only was this an ethical consideration, but respondents were actively informing research practice and discourse. Other studies have also used the term memory problem rather than dementia (Beattie et al, 2004). Similarly, respondents in Gillies' (2000: 366) study contextualised their experience within the normal ageing process.

It is not uncommon for close friends and family members to prefer not to tell the person their diagnosis in an attempt to avoid distress and to protect the individual. An ethical dilemma arises for researchers in such cases: are they colluding with those who have not informed the person that they have dementia (Gillies, 2000: 368)? To avoid any potential for collusion and to treat respondents with respect, protecting their rights and following the ethical principle of justice[xxxii] (Bjørneby et al, 2004), I concluded that although all respondents referred to the study had to have a diagnosis of dementia, it was at their discretion to name it as they wished. In the absence of standard guidelines on disclosing a diagnosis in Ireland, it was at the discretion of practitioners and family members to inform the person they had dementia. It later transpired that the majority of people in the sample referred to dementia as a memory problem, or stated that they had some memory loss.

4.5.5 Capacity

I felt that it was important for the success of the researcher that respondents were able to engage in the process. This can be crudely deemed as capacity to participate. The following definition from the Law Reform Commission was used as a marker to indicate capacity, where capacity is "a threshold requirement for persons to have the power to make enforceable decisions for themselves...to be autonomous and capable of self-determination" (The Law Reform Commission, 2005: 19-20). Capacity generally refers to a person's ability to perform tasks (The Law Reform Commission, 2005: 19). There are no guidelines in Ireland for assessing capacity to include people living with dementia in research unlike for example in Scotland (Scottish Mental Capacity Act, 2005). However, the Law Reform Commission's definition and their guidelines on capacity were considered useful for the purposes of this study.

If we apply a social (disability) model to how we view people living with dementia, we need to focus on retained ability over assumptions of expected inability. A functional model of capacity assesses a

[xxxii] Justice is to treat people fairly.

person's ability to make a particular decision: "the fact that a person belongs to a category of people (those with an early-stage dementia) who are often unable to make decisions for their own wellbeing, may open the possibility of a lack of decisional capacity – but it does not of itself resolve the matter. Furthermore, an assessment that a person lacks legal capacity in relation to one decision does not mean they lack legal capacity in relation to a different type of decision" (The Law Reform Commission, 2005: 46). Therefore, people were given the opportunity to take part and incapacity or disability was not assumed.

4.5.6 Informed voluntary consent

Respondents' ability to participate was addressed at three stages. At any of these stages it could have been decided that the person did not meet the inclusion criteria. At any stage respondents could secede they no longer wished to participate. The first stage was at the time of referral (from the Outpatient Clinic). The second stage was when possible participants were seen by a doctor who assessed[xxxiii] them for capacity. The third stage was during my first visit to their homes. An aspect of this visit was to outline the study and to assess potential participants for their suitability, ability and willingness to take part. If this was successful, the first interview was often conducted at this time. When all three stages were successfully completed, written consent to participate was sought.

A useful tool in supporting ability was to revisit consent and remind respondents of their participation (Wilcock, Romola and Bucks, 1999), giving them the opportunity on a number of occasions and at various intervals to decline participation. As a result, verbal consent was sought during the first contact in the hospital, over the telephone and at both interview stages. It was possible that respondents might have forgotten that they gave consent, even if they had capacity under the above definition and had given informed, meaningful, voluntary consent at an earlier date. Therefore, consent was revisited at each

[xxxiii] The clinical dementia rating scale (CDR) provided a validated scale to assess level of capacity.

interview stage and written consent was obtained before the first interview was conducted. Berg (2004: 64) describes informed consent as "the knowing consent of individuals to participate as an exercise of their choice, free from any element of fraud, deceit, duress, or similar unfair inducement or manipulation". Hansson (1998) as cited by Reid, Ryan and Enderby (2001: 381) points out a number of components for obtaining voluntary consent: (i) information is given in a way that is fully understood by the prospective participant, (ii) a sufficient degree of voluntarism is assured and (iii) authorization is acquired from the research participant. This reinforces the person as an autonomous research participant.

A modification of autonomy, 'voluntarism' encapsulates the ethic that all participants must voluntarily consent to take part in the research. Autonomy is about respecting the decisions, dignity, integrity and preferences of the person (Bjørneby et al, 2004). It is attained through an awareness of the aims and objectives of the research and an understanding of the required level of participation. A core aspect of the research was that informed voluntary consent was necessary to ensure that respondents had a genuine choice in whether or not to take part. A benefit of informed consent is that it can be empowering and enabling. The research is laid bare for participants so they can choose whether or not to take part.

Recent research has indicated that the greater the person's memory and cognitive disability, the greater their risk aversion and the more conservative their attitude towards involvement in research (Kim, Cox and Caine, 2002: 800). These authors suggest that the concern that people living with dementia might be more exposed to high levels of risk because of poor judgement may be exaggerated. For respondents in this study, participation held no physical risk, in contrast to participation in medical/clinical trials. However, there was a possibility that distress might be caused due to the nature of topics and themes discussed.

Dewing (2007) identifies a method to gain informed, meaningful consent from people living with dementia as 'process consent'. This method is more applicable to people who have more advanced dementia but is adaptable for people in the early stages. Although I did not read Dewing's 2007 article on 'process consent' until after data collection, many aspects of this approach were applied in this study. For example, access not proxy consent was sought from care-partners and capacity to give consent was also established before I sought written consent. Table 4.1 gives a breakdown of the fundamental components of the process consent method.

Table 4.1: The process consent method

Background and preparations	• Transparency is a principle where Gatekeepers are made aware of the purpose of involvement* • Permission is sought from gatekeepers (staff, family members, care-partners) to contact person with dementia* • Access, not proxy consent, is being sought *this may not be necessary
Establishing the basis for consent	• Establishing a basis for capacity to consent • Identifying triggers that influence a decrease in well-being • Identifying how people usually consent to activities of daily living
Initial consent	• Moving from what is known of consent and assent to the specific situation • Providing information to the person • Identifying the most appropriate way to disclose information to individual participants
Ongoing consent monitoring	• Ensuring initial consent is revisited and re-established at every meeting • Possibly ask a validator to sit-in on consent process
Feedback and support	• Agree feedback with person with dementia to be given to their care supports • Consider support that respondent might need once they leave the research context

** Table adapted from Dewing (2007)

Respondents were made aware of any risks they might incur if they became involved in the study. Putting the principles of autonomy and voluntarism into practice required the development of straightforward information sheets (see Appendix B) using easy-to-understand language. The consent forms (see Appendix A) comprised a series of yes/no questions that sought to ensure that the respondents understood the research and what their participation would entail. Discussions with respondents on the topic of consent also gave them the opportunity to ask questions. Other issues addressed in the consent form included (i) understanding that participation would not have any effect on their access to or receipt of health services, (ii) they had the right to stop or drop out of the research at any time and (iii) their signature indicated consent to take part. Forms were printed in large font and similarly to the information sheets they were written in easily comprehensible language with the view to compensating for some of the symptoms of dementia (for instance, confusion can be magnified by complex language and two-pronged question structure).

4.5.7 Additional ethical considerations

In the above sections many ethical issues have already been discussed, however researching dementia in particular requires the systematic implementation of ethical principles and practices. Following established ethical guidelines protects the respondent as well as the researcher. Informed voluntary consent (which incorporates the ethical principle of autonomy) has already been described, as has the nature of conducting sensitive research. Other ethical issues included nonmaleficence[xxxiv]/non-exploitation, beneficence[xxxv], confidentiality, utility and the assurance that people could express their views freely without fear or risk of any adverse responses from service providers.

[xxxiv] This is to do no harm.
[xxxv] This is to do positive good.

Nonmaleficence

Cotrell and Schulz (1993: 208) state that researchers need to recognise that research including people living with dementia may place an additional burden on both the care-partner and the respondent and efforts should be made to address issues of privacy, time expenditure and emotional strain. Nonmaleficence as an ethical principle contends that participants should not be harmed or subjected to harm as a result of taking part in the research (Virnig, Morgan and DeVito, 1999: 290). This can also be described as the principle of nonexploitation (Harris and Dyson, 2001: 645). Whether this aim is fulfilled depends on the integrity and awareness of the researcher who provides information and manages the recruitment process. I was aware that I was gaining a lot more than the respondents in this study from their participation. My awareness of the potential of exploitation meant efforts were made to ensure that no undue stress was caused to respondents because of their involvement in this research. For example, the length of interviews was determined by the interviewees and I was vigilant in watching out for any verbal or non-verbal signs of distress (such as becoming upset, looking uncomfortable, nervously fidgeting or becoming distracted). When I noted any signs of distress, I talked to the respondents about my observations and gave them the opportunity to withdraw or change topics. Respondents were informed that they could refuse to answer any questions and could terminate the interview at any time. Although there were no tangible benefits for respondents, I hoped that the experience would in some way be enjoyable and not difficult or unpleasant. The overall aim of the study was to do positive good and in this way beneficence was adhered to.

Location and surroundings

The location of interviews also had ethical implications. People living with dementia can find changes in environments and unfamiliar surroundings distressing (Goldsmith, 2002: 163). Following the general guidelines of qualitative research where research is undertaken in naturalistic settings (Bassett, 2004: 5), all interviews were conducted in

respondents' homes. I felt that It was important that respondents felt at ease and relaxed and being in their own homes helped to achieve this. In all cases people were given the choice to have someone else present while they were being interviewed. However, in all but two cases the person with dementia chose to have the interview in the absence of a third person. Conducting interviews in the person's home also provided rich contextual data. For instance I was able to observe whether any adaptations to the home had been carried out to accommodate the person's dementia. For example, a large clock hanging in the kitchen of one respondent's home displayed the day and date and this provided a relevant topic for conversation and broke the ice. It was important to place the person in the context of their life, where did they live, how did they live, did they have easy access to conveniences, were they living in a bungalow or two-storey house? I could elicit this information from observations rather than having to ask the person directly.

Confidentiality

Confidentiality as an ethical principle refers to the non-disclosure of information given by respondents under identifying characteristics. Respondents in this research were not anonymous, as I knew who they were and where they lived. However, every effort was made to remove from the research records identifiable information or characteristics. Respondents were assured of confidentiality and that their names would not be disclosed when the research was reported in this thesis. The question arose as to how confidentiality was contradicted if respondents needed referral to other services. Where a respondent needed further support, rather than personally refer them to another agency/body, I gave them phone numbers and encouraged them to seek assistance. On a number of occasions, after speaking to the person with dementia, their care-partner asked for my opinion on how they were doing and on their prognosis. Naturally, any information disclosed in interviews could not be relayed to family members as confidentiality had been assured. In general, experiences such as these reinforced the sensitive nature of the research.

Utility

There is an ethical responsibility to make good use of data collected (McColgan, 2003) and to disseminate information appropriately and extensively. This raises the question of utility: how useful is this research? It is hoped that this study will (i) add to the existing body of knowledge on the lived experience of dementia, (ii) give insight into including people living with dementia in research as service users and valuable contributors to this field of enquiry and (iii) give insight into the experiences of people living with dementia within the Irish health and social care system.

4.6 Data Collection and Analysis

Data collection took place between November 2005 and June 2007. The first part of data collection consisted of observations at the site of the referring service provider (the Age Related Health Care Out-patient clinic), where recruitment for the study took place. The purpose of this observation was to help me understand what going through the secondary care system is like for an older person. Recruitment began in November 2005 and ended in May 2006. From February to June 2006 interviews were conducted with people living with dementia and with their care-partners. Interviews with policy experts took place between April and June 2007. The following section looks at the different stages of data collection, from ethical approval to recruitment and sampling.

4.6.1 Ethical approval

Ethical approval was only sought once the aims and objectives, interview schedules, consent forms and information leaflets for the study were developed. As already stated a large urban-based hospital was approached to aid in identifying possible participants through their Age-related Outpatient's Clinic. It was agreed that I would attend the weekly Outpatient Clinic at this hospital, where I had the opportunity to meet potential participants. Approval was sought from the same hospital's Research Ethics Committee in October 2005. This Committee reviewed the confidential research

protocol[xxxvi], consent forms, information leaflet for service providers and research protocol[xxxvii]. Approval was granted in November 2005. Under the conditions of the approval, I had to seek consent from geriatric consultants working in the hospital's Outpatient department to approach and recruit possible participants.

4.6.2 Recruitment procedure

The referral body saw, on average, 25 – 30 older people each week. As the number of people attending who possible had dementia varied from week to week, recruitment was sporadic. The majority of people going to the clinic lived in the catchment area of the hospital and were referred to the clinic by their GP, or had been attending the day hospital (see Chapter Seven, section 7.3.2 for further information on referrals). Therefore, all respondents were using the same pathways to accessing services and all were receiving secondary care (hospital care). In most cases, they had similar (lower) socio-economic backgrounds, living in the Walkinstown and Tallaght suburbs of Dublin.

Each week the clinic's liaison nurse identified possible participants who would be attending the clinic and who met the study's entrance criteria. All attendees had already been diagnosed with dementia or had a Mini Mental State Examination score[xxxviii] (Folstein, Folstein and McHugh, 1975) between 20 and 28 and were being referred because of their memory. A list of possible participants was then drawn up and at the invitation of consultants and with the consent of the person attending the clinic, I was introduced to possible participants with a view to clarifying whether the person was willing to be contacted about the study in the future.

Each potential participant was given an information sheet when they first met me at the referral site. As mentioned above, it was important

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[xxxvi] This is a specific protocol sent by the committee for completion by the researcher.

[xxxvii] This was a 3,000 word summary of the project, which outlined the aims and objective, methodology, literature review and relevance of the research.

[xxxviii] Notwithstanding its critics, the MMSE is still the most commonly used scale to estimate cognition.

to build trust and rapport and the association with the hospital and with Trinity College, a well known university in Ireland, further facilitated this. Once verbal consent was given, at this initial stage, and agreement given to be contacted again in the future, a letter was sent to the potential participant, followed by a telephone call a few days later to make an appointment for the initial home visit. All interviews took place in respondents' homes, at a time and date most convenient for them. All contacts with respondents and their families occurred in short succession, partly to not prolong the process.

4.6.3 Designing interview schedules

When designing the schedules I wanted to be sensitive to aspects of dementia, such as short-term memory loss, disorientation and confusion. For example, when asking questions I worded them in straightforward language and there were no double-barrelled or two-pronged questions as recommended in the literature (Goldsmith, 2002: 58). My work on another study on dementia[xxxix] already mentioned (see chapter one, section 1.1) carried out before starting this thesis influenced my approach to the design of the interview schedules. People living with dementia were also included as research participants in that study albeit investigations into the lived experience were not to the same extent as in this thesis. I had experience of utilising more structured interviews with people living with dementia and also experience administering measurement tools (Brod Dementia Quality of Life Scale). This effected how I drew up the interview schedules for this thesis, as shown in Appendix C. However, the application of the schedules differed greatly to their appearance as I adhered to an IPA approach of flexible interviewing using probes and prompts.

As this study is exploratory and non-representative of the whole population of people living with early-stage dementia and as IPA requires data on the quality and texture of the person's experience (Willig, 2001: 53), contextual information was extremely important and

[xxxix] ENABLE – enabling technologies for people with dementia.

as much of this as possible was collected. Section 4.2.1 describes the IPA approach in greater detail. The principles of the approach were adhered to in the themes addressed in the interview schedules e.g. interest in the personal lived experience; how people apply meaning to their experience and meaning for the person is in a form understandable to them.

Topics addressed in the course of the interviews also developed when I reflected on the purpose of the study. It began as an investigation into the lived experience of dementia which addresses questions such as 'do you have a memory problem?' 'can you tell me what it's like', and 'activities of daily living/independence'. I wanted to place the 'micro' individual experience of dementia within a broader or 'macro' context and hence another focus of data collection became the respondents' experience of the health and social care system. As a result, broad topics such as 'diagnosis and experience of disclosure' (particularly in light of the fact that there are no national guidelines on diagnosis) and 'support services, needs' were incorporated into the interviews.

As Chapter Three indicated, an initial literature review was carried out to examine the lived experience of dementia in the light of secondary literature and to gather information on including people living with dementia in research. Themes identified relating to the lived experience included awareness of the illness, coping strategies, management techniques, interaction with the social world, effect of other people on the person's experience of dementia including stigma. Combined with the pilot interviews which were carried out in the months preceding recruitment this reflection on the literature helped to identify the key interview topics, while remaining committed to flexibility in my approach to carrying out the interviews. The pilots also helped me to hone my approach to respondents. They also acted as a type of pre-test to ensure that the topics addressed during the interviews were relevant and easy to understand.

The literature reviewed was also a helpful guide to how best to collect the data with respect to wording of questions. It was also important to examine the type of information other researchers had focused on in relation to the lived experience of dementia. However, I made a conscious decision not to overly review the literature in case this might add bias to the analytical process. For this reason, a more thorough review of the literature was undertaken after the analysis was completed. This was also instrumental in the discussion of findings, particularly as these two elements (findings and discussion) are presented together (see Chapters Five to Seven).

Data analysis was ongoing, which resulted in some topics being introduced in a conversational way under broader themes, for example going to mass and religious practices were suggested in the early interviews under the topic of social activity. Interestingly, themes which I thought would be highly relevant to respondents before data collection, such as the role of religion (Ingles, 1998) did not emerge as a major theme throughout the sample data. One respondent was a priest but he did not speak about his faith: he spoke more about his work and his work colleagues. However religion, identity and dementia is an area for further research

In order to maximise data collection and ensure data reliability the two face-to-face interviews with respondents were carried out in the space of a week. it is recommended in much of the literature that at least two interviews should be carried out if people living with dementia are being included in the research process (Clare, 2003; Friss Feinberg and Whitlatch, 2001; Froggart, 1988; Proctor, 2001; Sperlinger and McAuslane, 1994). This gives the person with dementia the opportunity to become familiar with the interviewer and it gives the interviewer the means to assess the extent to which the person had enduring concerns across two interviews (Sperlinger and McAuslane, 1994: 4). It was also important that respondents did not feel overwhelmed by a one-off lengthy interview. Carrying out two interviews also enabled my examination of consistency of

responses over time. See section 4.6.6 for a breakdown of the type of information collected in phases two and three of data collection.

4.6.4 Sampling and inclusion criteria

Purposive sampling was used to recruit people for the study; this approach allowed me to choose participants based on some feature or process that I was interested in: "Purposive sampling demands that we think critically about the parameters of the population we are interested in and choose our sample case carefully on this basis" (Silverman, 2006: 129). There is some evidence to suggest that the diagnosis of dementia in Ireland is low (Cahill et al, 2006: 322). Therefore, the pool of suitable participants for this study was already limited. As one of the inclusion criteria was that respondents had to be willing to discuss their experiences of having a memory problem the pool of possible participants was furthered limited.

Having an inclusion criteria helped to minimise the number of unsuitable referrals and limited the number of drop-outs. People living with dementia who were eligible to participate in the research were required to:

- Have a diagnosis of mild to moderate Alzheimer's disease, Vascular Dementia or mixed Alzheimer's disease and Vascular Dementia according to the Diagnostic and Statistical manual-IV[xi]
- Be aware of their memory problem and be willing to talk about it
- Live in the Dublin area
- Reside in the community

[xi] The Diagnostic and Statistical Manual of Mental Disorders, fourth addition (DSM-IV-TR) is the reference source used worldwide (World Health Organisation, 2006) and was a guide for this researcher and for the service provider who referred people for this study. All respondents had a diagnosis of dementia under the characteristics outlined in the DSM-IV-TR. The fundamental feature of dementia is the development of multiple cognitive deficits, which must be severe enough to cause impairment in occupational or social functioning and must be accompanied by a decline from a higher level of original function (American Psychiatric Association, 2000: 148). The DSM-IV-TR also gives guidelines on testing to ascertain levels of function in areas such as executive functioning, apraxia, spatial disorientation. For example, visuospatial functioning can be tested with a person copying drawings such as an overlapping pentagon.

- Be aged over 60 years[xli]
- Be able to give informed voluntary meaningful consent
- Have no major chronic illnesses or illness that required intensive medical treatment.

4.6.5 The Sample

A total of 41 people were identified as suitable for participation in the study and when I approached them at the Outpatients Clinic each gave consent to be contacted in the future. After further contact 24 of the initial 41 referrals met the full inclusion criteria and were suitable and willing to take part. Pilot interviews were carried out with three people (not included in the 41 initially approached) with Mild Cognitive Impairment and with one person with mixed Alzheimer's disease and Vascular Dementia (also not part of the original 41 suitable participants). Out of the final 24 people, seven dropped out after verbal consent was given and before all required data was collected. Reasons for not completing included unwillingness to take part after verbal consent given (2 people); entry into long-term care (1 person); family problems, it not being a good time for them (1 person); un-contactable (3 people). Table 4.2 displays a description of the 17 people who took part in the study.

Table 4.2: Characteristics of respondents living with dementia (N=17)

Gender	8 women 9 men
Age range	62 – 93 yrs (M = 77 yrs)
Diagnosis (diagnosis received between 2001 and 2006)	Alzheimer's disease = 12 Mixed Alzheimer's and vascular = 4 Vascular dementia = 1
MMSE	Range 14 – 28 (Mean = 23.05)
Clinical Dementia Rating Scale	.5 = 8 respondents 1 = 9 respondents
Economic Status	State (non-contributory) pension = 6 Employment pension = 6 Both State & private pension = 5
Living arrangements	Lives with spouse = 10 Lives alone = 4 Lives with spouse and one or more children = 2 Lives in a religious community = 1

[xli] People with early on-set dementia (under 60 years) were viewed as a unique group with other social factors to consider, e.g. cessation of work or managing with young families.

The sample consisted of eight women and nine men, whose ages ranged from 62 years to 93 years (Mean=77 years). All respondents had been diagnosed with a diagnosis of Alzheimer's disease (N=12), mixed Alzheimer's and Vascular Dementia (N=4) or Vascular Dementia (N=1). Diagnosis in all cases was made within the last five years, with many (N=8) being diagnosed in 2006 (no date of diagnosis was available for one respondent). The four respondents who had mixed Vascular and Alzheimer's disease were male (Mr. Burns, Mr Callaghan, Mr Barry and Mr Moore). Ten respondents lived with their spouse, two lived with their spouse and children and one respondent was a priest and lived in a religious community with a number of other priests. Four respondents lived alone.

It was important that respondents' care-partners were interviewed but in a number of cases (N=4) there was no-one available to participate either because the person with dementia lived alone or they were not yet in need of extra support. As a result 13 of the study participants had care-partners who also participated in the study.

4.6.6 Type of data collected

It has already been shown that data was collected from three sets of key informants, namely people living with dementia, their care-partners and policy experts. Length of interviews ranged from 12 minutes to one and half hours. See Table 4.3 for a breakdown of the length of interviews in each participant group.

Table 4.3: Length of interviews in minutes (N=53)

Respondents living with dementia **T0** **T1**	range = 20 – 92 mins (M=41.58) range = 12 – 50 mins (M=21.76)
Care-partner	range = 28 – 54 mins (M=38.46)
Policy expert	range = 41 – 88 mins (M=60.1)

Phase one included two interviews with each respondent, these occurred at Time 0 (T0) and approximately one week later at Time 1

(T1). As discussed above, the interviews covered a range of topics, such as:

- background and demographic information
- history of memory problem
- issues surrounding diagnosis
- experience of health and community services
- lived experience of the illness
- activities
- independence and support services (informal and formal)
- Sansone et al (1998) Preference Scale[xlii] (see below for further explanation)

The scores from standardised scales, used by clinicians who referred people to the study, were made available to me, these were:

- Mini-Mental State Examination (MMSE): this is the most commonly used scale to determine levels of cognitive function. It is an 11-item scale taking approximately 10 minutes to complete. In each respondent's case the referring body carried out the MMSE prior to referral and therefore this did not need to be carried out again. The MMSE scores also acted as a broad indicator of possible participants' suitability.
- The Clinical Dementia Rating Scale (CDR): this is another commonly used assessment scale to stage a person's dementia. It covers six domains; memory, orientation, judgement, community impairment, home and hobbies and personal care. These domains were rated by the referring service provider and I later examined these domains in the light of the qualitative interview data.

Although interviews were mostly semi-structured a number of closed structured questions were asked of respondents using Likert scales for responses (see questions 5 – 10 in section 5: Subjective experience in interview schedule, Appendix C). The reason I chose to include

[xlii] This was to examine consistency of responses over-time by asking the same four questions at different intervals and comparing responses.

structured questions and Likert scales in interviews was to examine a number of themes (such as awareness) in greater depth and to compare qualitative and quantitative responses to the same themes. The review of the literature (Chapter Three) highlights the complexities associated with awareness and dementia and I saw the interviews as an opportunity to examine this further. The literature presented in Chapter Three also shows how different disciplines gather information in different ways. I wanted to see if the quantitative and qualitative information given by respondents correlated, but in particular I wanted to explore the issues in much greater depth than the use of scales alone would have allowed.

It is also interesting to look back at areas which I originally thought would provide useful information but what emerged was very different. For example, I thought applying the Sansone et al (1998) Preference Scale (see Appendix C) would serve as a useful indicator of consistency of responses overtime, In actuality, it provided little if any additional information; it was too structured and respondents found the questions silly. Consistency of responses was evident from the qualitative data, where respondents spoke of the same issues across the two interviews and attitudes to certain issues did not change. Therefore, I decided not to present data on the preference scales in this thesis as it added little to overall findings.

The second interview with people living with dementia allowed for further discussions of themes raised during T0. These schedules were only developed once T0 interviews had been transcribed and after initial analysis had been carried out. Visiting respondents twice also took into account the fact that people living with dementia can experience good and bad days. They can have periods of greater or lesser engagement, and therefore visiting more than once gave me greater opportunity to conduct interviews during these more 'lucid' moments. If little information was elicited during the first interview, the second interview gave another opportunity to garner further insights of respondents' experiences. The second interviews also allowed for the validation of the content of the first interviews (Gillies, 2000: 367).

Phase two consisted of one interview (N=13, in four cases there was no care-partner available to take part) with respondent's care-partner, (in all incidences this was a family member). Table 4.4 shows care-partner characteristics. In the majority of cases (N=12) these interviews were conducted during my first visit and were all carried out in respondents' homes.

Table 4.4: Characteristics of care-partners (N=13)

Gender	8 females 5 males
Relationship to respondent	Spouse = 11 (6 women, 5 men) Daughter = 2
Living arrangements	Co-habiting with respondent = 11 Lives away = 2
Care-partner well-being (Greene Caregiver well-being scale)	Range = 19 -- 58 Mean = 33 (from a possible 75)
Work status	1 care-partner (daughter) worked part-time; All others were not in paid employment.

Most care-partners were female (N=8), either spouses or daughters and most lived with the person with dementia (N=11). Interviews in this phase provided additional collateral and contextual data and gave insight into the care-partner experience.

Interview schedules used with care-partners in phase two of data collection included the following sections;

- background and demographic information on care-partner and on the person living with dementia
- nature and level of care (if any) provided - informal and formal
- views on the coping mechanisms of the person with dementia
- relationship with the person with dementia
- the effect (if any) of dementia on them
- experience of health and support services

The Greene Carer well-being scale was also used. This is a 30-item scale that measures care-giver stress. People are scored out of a

possible 75, the higher the score the less stress the person is experiencing. As can be seen from Table 4.4 above, the care-partners' mean score was 33, which indicates a moderate level of stress.

Phase three comprised interviews with national dementia policy experts. There was some difficulty in identifying appropriate people for this phase of data collection as there are so few experts who specialise in social policy and dementia in the Republic of Ireland. Six policy experts were identified and took part in the study. Table 4.5 displays information about the policy experts interviewed.

Table 4.5: Organisation and role of policy experts (n = 6) and date and length of interviews

Organisation	Position within the Organisation	Date of Interview	Length of Interview
National Council on Ageing and Older People (NCAOP)	Director	12/04/07	52 minutes
Alzheimer's Society of Ireland (ASI)	CEO	16/14/07	68 minutes
Department of Health and Children (DOHC)	Nurse Adviser in Services for Older People and Palliative Care	30/04/07	43 minutes
Author of An Action Plan for Dementia	Professor of Economics and Director of the Irish Centre for Social Gerontology and author of An Action Plan for Dementia	18/04/07	42 minutes
Health Service Executive (HSE)	Care Group Coordinator, Older People's Services North Cork and Joint Chair of the Working Group on Residential Services for the Person with Dementia: Advancing the Agenda (HSE)	16/05/07	68 minutes
Health Service Executive (HSE)	Nursing Home Inspections, Former Manager of Services for Older People Dublin Mid-Leinster,	01/06/07	88 minutes

It was important that representatives from both the Department of Health and Children (DOHC) and the Health Service Executive (HSE) and non-governmental organizations committed to dementia care such as the Alzheimer Society were included. This phase of interviews was considered important in order to gain further professional and multi-disciplinary insights into the provision and development of dementia-related health and social care services. The intention was

to create a holistic and realistic picture of how people experience dementia within the health and social care system in Ireland. Themes raised by respondents were introduced in the interviews with policy experts.

These interviews, although adapted for each expert to cover their specific area of expertise, covered the following sections

- role in policy and service development
- their thoughts on national policy issues
- health and social care in the community
- future of dementia care in Ireland

4.6.7 Data Sources

By its nature qualitative analysis is an interpretive science. The process of analysis began when I first met participants and continued from there. All interviews were recorded once verbal consent was gained. T0 interviews were transcribed verbatim immediately after they were conducted which informed the development of T1 interview schedules as initial analysis was carried out at this stage. This followed the principles of Interpretive Phenomenological Analysis (IPA). Extensive fieldnotes complemented the data set, along with observational fieldnotes compiled during visits to the Outpatient Clinic. A large amount of data was therefore available for analysis. See Table 4.6 below for a breakdown of data types for the total of 53 interviews that were conducted and analysed.

Table 4.6: Data types: transcribed interviews (N=53), field notes and observations

	T0	T1	Other interviews	Field notes	Hospital observations
Respondents	17	17		17	17
Care-partners	13	*		13	13
Policy experts			6	6	
Total	30	17	6	36	30

* *No T1 interviews conducted with care-partners*

4.6.8 Data Analysis

Data analysis was continuous and commenced when data was first collected. All interviews, bar one, were tape recorded. These were transcribed verbatim within days of the interview. I took extensive fieldnotes of the interview that was not tape recorded. Interpretative phenomenological analysis was used to identify themes from the raw data. These themes subsequently led to the development of interpretations, understandings and theoretical insights. There was such an extent of raw data that the analysis took a considerable length of time. Initially I was focusing too much on individual details, as the experience is so unique without viewing the entire data set as a whole. The following section outlines how this data was analysed.

4.6.9 Applying interpretive phenomenological analysis

Interpretive phenomenological analysis (IPA) is "concerned with an individual's personal perception or account of an object or event as opposed to an attempt to produce an objective state of the object or event itself" (Smith, Jarman and Osborn, 1997: 218). IPA aims to collect the quality and texture of the person's experience (Willig, 2001: 53). It attempts to seek the meanings in people's statements and actions, thus illuminating the lived experience. There are two main elements to IPA, the first is to **'give voice'** (descriptive outcomes) and the second is the interpretative requirement to **'make sense'** (Larkin, Watts and Clifton, 2006: 102). The approach acknowledges that any exploration of respondent experience is always only an *interpretation* of the experience (Willig, 2001: 53).

Full sets of transcripts for two respondents were given to a health service professional working in the area of dementia. She was asked to reflect on what she felt were the meanings of respondent data, interpreting their experience and identifying their needs. This allowed for comparisons between my interpretations and those of the dementia worker, thus going some way towards addressing the issue of bias. In the main, her interpretations resonated with mine. Taking two interpretations of the same transcripts does not negate the subjective element of IPA but to some extent it helped to question

and validate the understandings and interpretations that I had initially drawn from the data.

As stated earlier IPA as a double process (Larkin, Watts and Clifton, 2006: 103). The first step is 'first order' analysis, which summarises respondents concerns. The objective is to produce a coherent, third-person description. The second part of the process is to undertake a more overtly interpretive analysis, placing the initial description into a wider social, cultural and theoretical context. In line with a common practice, the conceptual framework was used to shape this second part of the process. These interpretations are grouped or clustered into themes, and synthesised into a thematic picture that accurately reflects the nature and diversity of the issues and/or experiences.

IPA is not solely concerned with data analysis but is an approach operationalised throughout the research process. During interviewing this approach required that open-ended non-directive questioning was used, while more focused questions were used to encourage respondents to elaborate (see section 4.4.2 on in-depth interviews). Once interviews were completed and fully transcribed, transcripts were read and re-read (with T0 and T1 transcripts for each respondent viewed as a whole). A number of operational steps were then followed. Table 4.7 gives a breakdown of the steps used when applying IPA to raw data taking a thematic approach to data analysis.

Table 4.7: Steps for implementing IPA (Willig, 2001)

Step one	• Unfocused notes taken on general observations, thoughts and questions (usually in the left margin) • Transcripts are viewed individually
Step two	• Identify and label themes (usually in right margin) • Theme titles are conceptual
Step three	• Introduce structure into the analysis • Themes are considered in relation to one another • Natural clusters are developed • Hierarchal relationships between clusters developed

Step four	• Summary table of structured themes, combined with quotations that illustrate themes

4.7 Limitations

In common with all research, there were several limitations to the design of this study. In-depth interviewing presents some problems, for example what one says and what one means can differ, especially within the context of dementia, as vocabulary and speech may be affected. However, using IPA helped combat this problem by investigating all possible meanings of individual statement. I was aware, from the outset, that the lived reality of the person with dementia could be different to the perceived reality of others. When addressing the lived experience of dementia, the focus of interest is on the person with the illness, as they have real felt emotions, opinions and attitudes. This adheres to what Taylor and Bodgon (1998) state is the main interest of the qualitative researcher which is not truth *per se*, but rather perspectives. It is difficult to make conclusive statements about the lived experience as it is based on interpretations; however, as more and more original research is being carried out on dementia it is possible to compare findings to other original pieces of research on the topic.

Another limitation to the study was the length of time it took to conduct interviews. For this piece of research it was not a negative limitation. However, future research that includes people living with dementia should ensure that time restrictions are not placed on data collection and interactions with respondents.

This research was not truly participatory; a truly participatory research design demands consultation with people living with dementia at the development and design stage. It also should use reflexivity with those who participate, asking them to comment on completed transcripts which was not an approach used in this research. Participant action research is a developing area, which should be explored as a possible method for further research on and about

dementia. Therefore, the lack of reflexivity offered to participants is a limitation of this study.

Another limitation was the application of the IPA approach. The fact that a number of structured questions using Likert scales were asked of respondents living with dementia meant that IPA was not implemented in its truest form. The IPA approach did however affect other aspects of the design of the research, how I interacted with respondents and in how data was analysed. My own lack of experience of using this method was also a limitation. In hindsight fewer research participants would have provided the opportunity to undertake a greater level of interpretation of the data (see Chapter Nine for a further discussion of this under 'implications for further research' section).

This research consisted of a number of interviews with each respondent. However, a longitudinal approach could have yielded further data and could have further illuminated the lived experience.

All respondents were recruited through a Dublin-based Age-Related Hospital Outpatient Clinic. In this way participants were already receiving a particular and specialised service. As a result the sample does not reflect accurately the experience of all older people living with dementia who live in the community, especially those people who are not linked to any specialised services.

4.8 Chapter Summary

This chapter has outlined the research questions, methods and processes used in this study. The main aim of this study was to include people living with dementia in the research process and to listen to the accounts they provided about what life was like for them now that they were living with a dementia. A person-centred approach was used that placed the person at the centre of the design and analysis. Considering the inclusion and the needs of people living with dementia directed what methods and research approaches would

be taken. As a result, consideration of ethical issues was a large part of the research design and how data was collected and resulted in the implementation of strict ethical principles.

Qualitative semi-structured in-depth interviews were conducted with people living with dementia, with their care partners and with a number of policy experts. Interpretive Phenomenological Analysis was used and a person-centred approach taken to explore the lived experience. It was the main form of analysis used, again promoting the position of the person with dementia at the centre of the investigation. The following chapters report the findings that emerged from the application of the research design and methods described above.

CHAPTER FIVE: FINDINGS AND DISCUSSION I: LIVING AND COPING WITH DEMENTIA

5.1 Introduction

This chapter, the first of three core chapters that report on the study's findings, focuses on the lived experience of dementia. It explores what dementia means to the person and how people and their care partners manage on a day-to-day basis, adjusting to the changes dementia brings about. The main themes identified from data analysis on the lived experience were: (i) awareness of dementia, (ii) responses to the onset of dementia and (iii) coping. These themes naturally overlap as I found that, for example, emotional responses were linked to awareness. The chapter concludes with reflections on major findings relating to the main theoretical and conceptual influences on the thesis.

The literature suggests that insight is always partial and relative and demonstrates that there can be a discrepancy between the subject's view of reality and that of others (Howorth and Saper, 2003: 113). A particular interest in this chapter is the view of reality held by these men and women living with dementia and their insight into any changes in their lives since its onset, although the perspectives of care-partners are also discussed. In keeping with Kitwood's approach of person-centred care, reactions to having a dementia were found not to be solely based on the biological changes experienced but also on social, environmental and psychological factors. This also follows a social constructionist viewpoint, considering a person's awareness of the reality in which they exist, even if reported levels of awareness and experiences differ from the insights of others such as respondents' care-partners.

The findings presented in this and subsequent chapters emerged from a careful and rigorous analysis of the data. As outlined in the methodology chapter (Chapter Four), Interpretive Phenomenology

was used to guide the analysis. The crux of this approach is that all possible meanings of words and statements are first investigated. First order' analysis is initially applied which means summarising respondents' statements. The second part of the process is to undertake a more overtly interpretive analysis (Larkin, Watts and Clifton, 2006: 103). These interpretations are then grouped or clustered into themes, and synthesised into a thematic picture that accurately reflects the nature and diversity of the issues and/or experiences.

5.2 Awareness

Chapter Two examined the literature on the lived experience of dementia and argued that it is not accurate to assume that people living with dementia have no awareness of or insight into their illness (Phinney, 2002b: 330). For example, Killick and Allan (2001: 262) have questioned the 'hypercognitive conceptualisation' of awareness, which is a very narrow perspective as a person can be aware of many different things, not just those in the intellectual sphere. This was true of respondents in this study as their levels of awareness of different issues varied and in some cases fluctuated over time. Some respondents were aware of having dementia, others were aware of changes in their memory and cognition even though they did not speak about dementia *per se*.

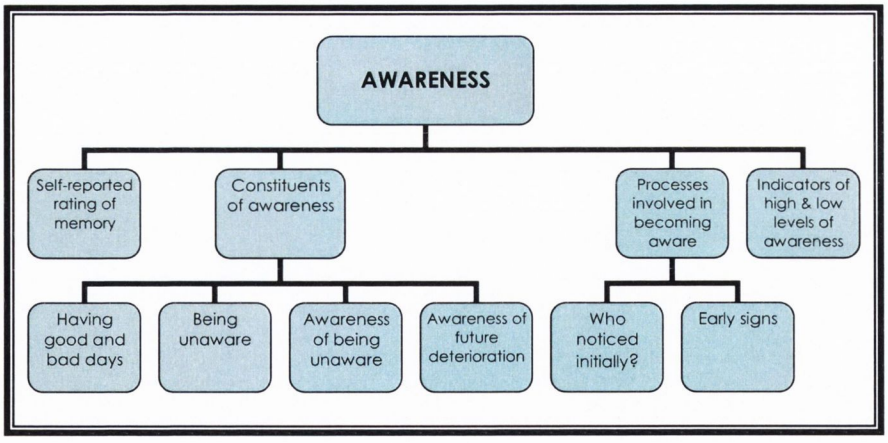
The first part of this section on awareness examines respondent's self-reflections on their memory. Although awareness and memory are not the same thing, how respondents viewed the functioning of their memory was connected to how aware they were of their memory loss problems or dementia and its effects. I refer to awareness of the effect or symptoms of cognitive and memory change as symptomatic awareness.

The second part of this section examines the constituents of awareness. From the data collected, four broad elements of awareness emerged. These included (i) having good and bad days,

(ii) being unaware, (iii) awareness of being unaware and (iv) awareness of future deterioration. Finally, this section on awareness examines the processes involved in becoming aware (of dementia or awareness of memory and cognitive changes/impairment/disability, as not everyone identified themselves as having a dementia, even though they all had a dementia diagnosis). In six cases respondents had been told they diagnosis and in 11 cases they were told in softer terms that they had a deteriorating memory problem. These processes were separated into two analytical categories, namely 'who initially noticed changes in cognition' and 'what were the early signs'. This section concludes with a list of indicators of high or low levels of awareness.

Figure 5.1 illustrates the connection between the themes discussed in this section. It shows how complex the whole topic of awareness in the context of dementia is and suggests that awareness is a very fluid term and can be influenced by one's social network (who noticed the signs and symptoms first and communicated their observations) and by the way in which the illness presents (early signs). A further discussion of this model is undertaken in the section summary, see section 5.2.5.

Figure 5.1: Themes related to awareness



5.2.1 Self-reported levels of awareness

There has been some debate in the dementia literature on how to assess and measure awareness. Zanetti et al (1999) stated that there is no gold standard in its measurement, assessment or in determining levels of (un)awareness. Therefore, I used two different methods to examine self-reported memory loss awareness with respondents. First some open-ended questions were asked and qualitative data on how respondents spoke about their memory loss experiences was collected. I also used a structured question on how respondents viewed their memory. At the beginning of each interview, all respondents were asked an initial general question about their memory ('Do you have a memory problem?'), followed by another open-ended question ('Can you tell me about this?'). More detailed questions were then asked addressing more specific themes such as what were the kinds of things they forgot, when they first noticed changes in cognition and memory and how it affected them psychologically and emotionally. Respondents were also asked to assess their own memory status using a five-point Likert scale. Although this is a qualitative investigation, I wanted to use a structured element to gather data on awareness because this approach is a relatively straightforward way to investigate a complex area. Using Likert scales can also be an effective way of gathering data on self-reported attitudes and behaviours (Hartley and MacLean, 2006: 813). I thought it would also be interesting to see if respondents' reports of their memory problems would be positive or negative. Table 5.1 reports results of the structured question on self-reported memory problem collected at baseline T0 interviews;

Table 5.1: Self-reported level of memory problem at T0

Self-rating of Degree of Memory Problem ('How would you rate your memory problem? Very bad, bad, neither good nor bad, good or very good')	Very bad = 2 Bad = 2 Neither good nor bad (Okay[1]) = 8 Good = 4 Very good = 0 No comment = 1

[1] Respondents recognised the category neither good nor bad as being OK.

Although respondents were asked to rate their memory problem, the questions was somewhat ambiguous and their interpretation of the question was how would they rate their memory? Four respondents (010-Mrs Curran, 023-Mr Burke, 033-Fr Hanrahan and 038-Mrs Gannon) reported that they had a good memory and four others (004-Mrs. Beattie, 018-Mrs. Buckley, 030-Mr. Murphy and 036-Mr Moore) said they had a very bad or bad memory. Most respondents (N=8) however felt that their memory was 'O.K.' (017-Mr Burns, 020-Mr Watts, 024-Mrs Griffin, 029-Mrs Lynch, 032-Mr Barry, 034-Mr Doyle, 035-Mrs Doherty and 041-Mrs Martin). Interestingly only three respondents (004-Mrs. Beattie, 018-Mrs. Buckley and 030–Mr. Murphy) spoke openly about having dementia (rather than referring to it as a memory problem they spoke about having Alzheimer's disease). These findings concur with the literature on the use of Likert scales with people with an intellectual disability. Hartley and MacLeon's (2006) review of the use of Likert Scales in intellectual disability research found that people (particularly those with a moderate to profound intellectual disability) had a tendency to choose positive response alternatives in Likert scale questions, what they refer to as a positive bias. In a different study, (Cahill et al, 2004) where the Brod quality of life scale was used, self reported ratings on quality of life by people living with dementia interestingly were more positive than others might expect across a three and six month period.

Mr Watts (020) who reported having an 'Okay' memory, i felt (020–Mr. Watts) displayed no insight into his memory loss. He never referred to having any memory change and he felt his memory was 'Okay'. Reflecting on the ways in which Mr Watts differed from other respondents who said that their memory was 'Okay' or good I noted that he displayed no anger or offence when the topic of memory functioning was discussed. The symptoms of dementia he experienced included short-term memory loss and he often repeated statements and questions, he did not like being left alone, he no longer went out alone and he had agnosia and was failing to recognise many family members.

Although a large number of respondents reported their memory was good or 'Okay', analysis of the qualitative data revealed somewhat contradictory findings. In other words, the quantitative approach using the five-point Likert scale was not entirely accurate in reporting the reality and failed to provide a valid account of peoples' circumstances. If I only used a Likert scale as the measure to assess awareness, comparing respondents' answers to collateral sources, this approach would suggest that they had little or no awareness.

An alternative interpretation of the above is that they were attempting to give socially desirable responses to this probing question. Often later on in interviews or during subsequent interviews with respondents, those who reported a good or 'Okay' memory spoke about the symptoms of memory and cognitive disability in great detail. This supports Killick and Allan's (2001: 262) findings that people living with dementia can be aware of a number of different changes rather than being aware solely of cognition/memory problems or dementia. For example, a person can recognise changes in their personality and their emotional responses to situations. Mrs Curran, who reported her memory/memory problem as good spoke about becoming disorientated at home (see section 5.2.4); Mrs Griffin said she covered up her memory problem (see section 5.4.1); Mr Burke (who on the Likert Scale rated his memory as good) accepted that his GP said there was something significantly wrong with his memory (see section 5.2.2); both Mr Burns and Fr Hanrahan spoke openly about their word-finding difficulties (see section 5.2.4) yet on the Likert scale he classified his memory as good. Throughout this chapter I will present other findings that show examples of some of the discrepancies found between the structured quantitative approach and the more inductive one. This suggests that directly asking someone with dementia how they rate their own memory functioning and using a quantitative measure gives a different indication of their insight into the level of the problem. This is supported by Howorth and Saper (2003: 121) and Seiffer, Clare and Harvey (2005: 540) who suggest that qualitative

data on awareness yields richer responses than quantitative measures.

5.2.2 Constituents of awareness

As mentioned earlier the constituents of awareness which emerged from data analysis in this thesis were having good and bad days; being cognitively unaware, awareness of being unaware and awareness of future deterioration.

(i) Having good and bad days

As mentioned in the literature, people living with dementia often have good and bad days (Pratt, 2001: 176). Therefore, levels of awareness can vary from day-to-day. Having good and bad days can refer also to people living with dementia recognising that their memory and cognition can fluctuate over time. It also refers to the person's varying insight into their impairment/disability across time; this is often referred to as having a lucid moment. People living with dementia can experience days when their memory is sharp and this can be followed by periods of greater forgetfulness. Some respondents in this study were aware that their memory could be good but also bad at times:

> *"Respondent: One day it's great (memory) and for that again I can't remember a thing (care-partner laughs). Interviewer: And how is it today? How do you feel today? Respondent: I think it's all right"* **(029, Mrs Lynch, female, 87 years, Alzheimer's disease, lives alone)**

Mrs Lynch's recognition of this difference illustrates an awareness and insight into her changing cognitive position.

Another respondent, Mrs Griffin, expressed different levels of insight at the two interview stages. She referred to her memory changes as normal ageing during the first interview but at the second interview she expressed stronger awareness of her dementia. I will explain and explore this further in section 5.4.1.

(ii) Being Unaware

Not all respondents outwardly indicated awareness of a memory or cognitive problem. Six respondents expressed a view that changes in their memory and cognitive were not significant. In one case (Mr Watts) I felt that his unawareness was due to neurological changes as he appeared content and happy with his life and did not perceive any significant changes. Comparing his transcripts to the other five respondents who reported that their memory was 'Okay' or good (Mrs. Curran, Mr. Burke, Fr. Hanrahan, Mr. Doyle and Mrs. Gannon) and who appeared to display little awareness, I noticed that these five respondents became angry, irritated and annoyed when memory and impairment were mentioned in the course of the in-depth interviews. Mr Watts displayed none of these emotions. It is possible that in these cases respondents were using denial as a coping mechanism. This follows Cotrell's (1997: 76) thinking on the distinction between denial-based unawareness, i.e. psychologically motivated and those whose lack of awareness is neurologically based. According to Cotrell, the former is evident when the person becomes more agitated when confronted with deficits caused by memory and cognitive impairment and the latter results in more perplexed and less emotionally reactive responses.

Mr Doyle provided a good example of motivated denial for he reported that he had reacted very negatively to receiving a diagnosis of Alzheimer's disease and was extremely hostile towards the medical profession. He could remember what the doctors had said but was unwilling to accept his diagnosis, as the following excerpt illustrates:

> *"Interviewer: And when you were up with the doctor did they mention anything about dementia or Alzheimer's disease? Respondent: The last time I heard any mention about that was the last time I was up with him. Interviewer: And what did he say? Respondent: He just said, apparently they had seemed to have a consultation, from what I can gather, like they all came to the one conclusion, that*

> *it was Alzheimer's. Interviewer: And how do you feel about that? Respondent: I feel perfectly normal, quite frankly I feel a lot of them, if they came to that conclusion, I think it's them that's due for Alzheimer's...I have no problems or anything like that. And as far as I'm concerned, okay the doctors have come to that conclusion that it's Alzheimer's and my own personal opinion is that they don't even know what they are talking about. They can't find anything wrong with me, so I'm, the easiest way out was to say Alzheimer's, that's my opinion of them"* **(034, Mr. Doyle, male, 76 years, Alzheimer's disease, lives with spouse)**

An alternative interpretation is that Mr Doyle did not notice his symptoms and may have been unaware of how his memory was changing. He was also rarely physically sick, therefore being told that he had a deteriorating illness may have been very difficult for him:

> *"I've had perfect health all my life. So basically for me getting sick was like something, I think the last time I was sick was about fifteen, twenty years ago"* **(034, Mr. Doyle, male, 76 years Alzheimer's disease, lives with spouse)**

However, reflecting on his social situation, I became aware that Mr Doyle had recently retired and remarried. His children were estranged and his wife was not coping with his diagnosis, as she had health and anxiety problems herself. In this way he experienced several significant changes in recent years, both in his domestic and work life having re-married and given up his job. Accepting a diagnosis of dementia would have meant having to accept further change. Weinstein et al (1994) as cited by Clare, Goater and Woods (2006: 765) call this an "operation of defensive denial as a self-protective psychological mechanism". This example demonstrates the importance of examining a person's life and social history to gain a more accurate picture of their situation.

In other cases, respondents spoke about there being no shame in implementing mechanisms to help them to manage, indicating that awareness can be implicit:

> *"Well I try to learn at the table (referring to a calendar where she writes notes and appointments), if somebody was coming or somebody was going somewhere, or if I had to go, if it was a few days later I do keep my eye on what's on the table...There's no shame in that"* **(041, Mrs. Martins, female, 77 years, Alzheimer's disease, lives with spouse)**

The way Mrs Martin mentioned the word shame suggests being embarrassed; embarrassed of forgetting things.

Interestingly, Mr Callaghan was the only respondent who refused to rate his memory (he said he could not answer the question) but he did refer to the effects of forgetting:

> *"There's no comfort about looking silly not knowing that today is Saturday, or is it? Is it Saturday"* **(039, Mr. Callaghan, male, 82 years, mixed Alzheimer's disease and vascular dementia, lives with spouse)**

Mr Callaghan did not want to answer in case he looked 'silly' he was aware that he might get the question wrong.

Some of these men and women found it difficult to explain or justify the changes they were experiencing and in this way to acknowledge the presence of a disability when they were still physically able to do many things:

> *"Well no, emm, I don't actually forget anything as far as I know because I can't be, I can't imagine being at a loss like that. I mean if I want to go somewhere I go there and emm, I walk a great deal you see. I walk"* **(023, Mr. Burke, male 78 years, Alzheimer's disease, lives with spouse)**

(iii) Awareness of being unaware

A number of respondents (N=4) were aware of their lack of cognitive awareness and realised that they lacked insight and awareness into what was happening to them. These respondents attained a degree of awareness based on what they had been told, rather than directly through their own personal experiences. In Mr Burke's case, he said that he could not imagine being at a loss, yet he accepts that his doctors said:

> *"Oh yeah, well when I was with my GP, I'm still with him but it's mostly now in the other people [outpatient's], but emm, he did mention it [memory problem] yes. Emm, he obviously told me, he must have told me. He probably told the hospital, but emm, it, I suppose if somebody asked me certain questions I get stuck in them, emm, if it's something now mechanical I can em, cope with it I think. Emm, I can pump the wheels or I can check out the level of oil and do all those things automatically without even thinking, so I don't be at a loss in any way"* **(023, Mr. Burke, male, 82 years, Alzheimer's disease, lives with spouse)**

Mr Burke's reaction to professional opinion about his memory is in direct contrast to Mr Doyle's since he demonstrates some level of acceptance. This could be because Mr Burke continues to enjoy the same activities, his car for instance. Other differences between Mr Burke and Mr Doyle are that at the time of interview Mr Burke was retired over ten years. He had a good relationship with his wife and his sons were in regular contact. He enjoyed getting out and about and was very active, walking every day. The two men's situations therefore differed considerably.

There were also a number of people in the sample who did not notice anything wrong with their memory, yet they did not discount that they had undergone some changes. They presumed that an element of memory loss was forgetting that you forget. While

respondents in this category may have been aware of their memory problem, they tended to forget it:

> *"I don't remember having the memory loss, you know what I mean"* **(032, Mr. Barry, male, 79 years, mixed Alzheimer's disease and vascular dementia, lives with wife)**

In this way respondents were aware of the processes involved in memory change. However, this awareness of unawareness occurred in a minority of cases.

> *"Well I don't see anything wrong with it (memory). And I suppose you wouldn't see anything wrong with yours either"* **(041, Mrs. Martin, female, 77 years, Alzheimer's disease, lives with spouse)**

Mrs Martin was looking for commonalities with other people, in this case me. It also suggests that she feels all people lack a level of insight or self-awareness.

(iv) Awareness of future deterioration

Some respondents reported higher levels of awareness of having a memory problem. However, while they recognised that something was wrong, they did not necessarily equate this with an awareness of having dementia, Fr Hanrahan's words provide a good example of this:

> *"Interviewer: And how would you rate your memory would you say that it is good, bad or in between? Respondent: Not bad anyway, but emm, it's hard to know, I have no problems like really you know. But I get stuck like in conversation I will get stuck for words sometimes you know but then when I'm flowing, I'm flowing"* **(033, Fr Hanrahan, male, 70, Alzheimer's disease, lives in religious community)**

In contrast, Mr Murphy's view and understanding of his situation was the opposite of Fr Hanrahan's. Mr Murphy had a high level of awareness of his dementia; in fact he felt his doctor was being

cautious in relation to his diagnosis. He also was aware of his prognosis:

> *"The doctor said it's the beginning of it you know. But I think it's a bit more than that"* **(030, Mr. Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

Therefore, another constituent of awareness was realising that one's memory and cognition was going to worsen and that having dementia meant they would deteriorate further. This challenges a myth surrounding dementia that the person does not know what is happening to them. Mr Murphy was very aware that in the future he would deteriorate and his level of awareness would decrease so much that it would no longer be an issue for him;

> *"I suppose if it gets too much I won't fuckin' know anything about it, sorry for cursing. It's a... I won't know anything about it"* **(030, Mr. Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

His use of strong language reflects the high level of emotion attached to this realisation. Armed with this knowledge he is also aware that it is those around him that will have to help him manage as he gets worse. Already, at the time he was interviewed he relied on his wife to remember appointments:

> *"But I, I hospitals and all that sort of things you know, May has all that you know, I would never know, I think I have to go next week"* **(030, Mr Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

Three respondents (Mrs Beattie, Mrs Buckley and Mr Murphy) who all had a high level of symptomatic awareness and were aware of possible future deterioration were unsure about the future and had many questions about what would happen:

> *"Interviewer: Do you have any fears for the future? Respondent: Well, the only one I have is that if this multiplies, will it? I mean Alzheimer's, does it run in families?"* **(018, Mrs. Buckley, female, 78 years, lives with spouse, Alzheimer's disease)**

> *"Can it be cured?"* **(004, Mrs. Beattie, female, 67 years, Alzheimer's disease, lives alone)**

> *"I don't know why, you know. I don't know why, whether I should be moaning about it, what's going to happen to me?"* **(030, Mr. Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

These examples vividly illustrate the need and urgent quest for more information on prognosis, particularly in the case of people who have high levels of awareness. Information helps people to understand what is happening and gives them a sense of balance in what to expect. This theme of information and feedback will be further examined in Chapter Seven. However, for others the prospect of understanding their prognosis was hugely unappealing:

> *"I don't know that I would like to know anymore about it. I don't know whether it's going to get worse or not, you know and it would be no use knowing"* **(018, Mrs. Buckley, female, 78 years, Alzheimer's disease, female, lives with spouse)**

Accordingly every person living with dementia should be treated on an individual basis and information on prognosis should be given to them according to their wishes.

5.2.3 Becoming Aware

An important element of awareness was the process of 'becoming aware'. While analysing the data on gaining awareness I noticed the similarities with Keady and Nolan's (1994) psychosocial categorisation of dementia (see chapter 2, section 2.5). For the purposes of presenting the findings I adapted their categorisations applying it to the theme of 'becoming aware';

- the person (or someone close to them) notices initial slips
- these slips become more frequent
- the person (or someone close to them) notices changes in their interactions with other people
- they begin to refer to or acknowledge their changed cognition

- their memory and cognitive disability begins to have an effect on their ability to interact with others

(i) Who notices initially?

In this study, recognition of the disability and impairment often occurred when the person or someone else first noticed the signs of memory and cognitive change and talked about this, this then developed into a sense of awareness of having dementia or that it was more than age-related memory change. In the majority of cases where respondents were married, respondents' spouses (N=7) noticed that the person was experiencing some memory changes (Mr Burns, Mr Watts, Mr Burke, Mr Barry, Mr Doyle, Mrs Gannon and Mrs Martin). In three of these cases, care-partners initially noticed something was wrong when they were out in company or in unfamiliar surroundings. In these cases they said that it caused them some embarrassment. Moving away from home into other social situations possibly sharpened their observations and highlighted the fact that what was happening might be more than the person just 'having a bad night':

> *"...and it was just happening more frequently and then if you're in company and if you're with people for a lot of time and it seems to be happening, you notice it more then. Then I really noticed it, I may have noticed it before we went away but I didn't put pass on it because it didn't effect us but when you're in a group like that you're kind of conscious of it. You're conscious of him being stuck for words the whole time, you know"* **(C017, Mrs. Burns, care-partner, spouse)**

Mr Burn's interactions with other people highlighted his memory/cognitive difficulties. Mrs Burns worried about how others viewed him and what others would think. This meant that the changes he was experiencing had greater significance for her. I think this is a good example of how other people contributed to the growing awareness of dementia. For Mrs Burns, this gave her husband's situation greater and graver significance.

For Mrs Barry her growing awareness came about through a social situation where her husband's behaviour appeared to her both different and socially embarrassing, breaking normal social etiquette:

> *"We were at, its gas you start thinking back and things happen you know. I remember we were out one night with friends of ours that were home from Canada and Seamus went up and I went up, I was embarrassed the way he filled his plate, it was self-service you know and then he let a copper coin, a pound coin fall on the floor. Well he done, he nearly killed himself trying to get it. And I said 'leave it'. So little things like that, which normally you'd say 'good luck to the sweeper' or I wouldn't fill his plate the way he did you know. That was just two stupid little things"* **(C032, Mrs Barry, care-partner, spouse)**

In another case (Mr Watts) it was changes in his routine which resulted in his wife too noticing that his perceptions had altered:

> *"We were having dinner one night in the hotel and it was lashing and he said how are we going to get home it's raining, it's lashing raining out there. He didn't realise that he was actually staying in the hotel you know"* **(C020, Mrs Watts, care-partner, spouse)**

Interestingly, in five cases (Mrs Beattie, Mrs Curran, Mr Murphy, Mrs Doherty and Mr Moore) respondents themselves noticed the early signs of memory and cognitive change. Yet in a number of these cases, respondents did not initially take action to address them:

> *"Interviewer: And what things happened that made you notice that the memory was getting worse? Respondent: The fact that people who I knew quite well and I, I couldn't think of their names and (long pause). Interviewer: How did that make you feel? Respondent: Mad. Interviewer: Mad. Did you talk to anyone about the memory loss? Did you go to your*

GP or who did you talk to about it at the time? Respondent: Well I didn't at the time. I think I just went on, it was when I went to the hospital the last time (long pause)" **(036, Mr Moore, male, 93 years, mixed Alzheimer's disease and vascular dementia, lives alone)**

"Interviewer: And when did you first notice that you were starting to forget things? Respondent: It was speaking mixed up and writing, not last year the year before. Interviewer: What did you do about it? Did you talk to anybody about it? Respondent: Oh I went to my own Doctor. I didn't tell him for a good while, you know I thought maybe it would go away. But my friends were saying but 'Betty you'll have to tell because you'll have to'. But then it was more the speech and the writing rather than the, rather than the memory. And they'd be laughing and all and I'd be laughing you know we'd all laugh. But immediately my own Dr. -------- referred me to... (pause) Interviewer: -------- (name of consultant)? Respondent: Yeah. Interviewer: Okay and did your daughters notice? Respondent: Yeah. Interviewer: So you were kind of hoping it would get better by itself? Respondent: Yes, yeah. I could have coped with saying things back ways. Once when I was receiving the Eucharist I said thank you very much goodnight. Instead of amen (both laugh)" **(004, Mrs Beattie, female, 67 years, Alzheimer's disease, lives alone)**

In both of these cases Mrs Beattie and Mr Moore did not tell anyone when they first noticed symptoms. They hoped that they would go away or get better. They were still coping and did not feel the need to seek any intervention or help. This may partly explain why early diagnosis often does not occur.

In three other cases (non-spouse) family members noticed the signs and symptoms first (Mrs Buckley, Mrs Griffin, Mrs Lynch and Mr Callaghan):

> *"Interviewer: When did you first notice that you were having a little bit of a problem with your memory? Respondent: Well, I think it was when, I suppose Harriet (daughter) spotted it probably and eh she told me and I go on from there. Then in the hospital, of course, there was a few questions there as well"* **(024, Mrs. Griffin, female, 75 years, Alzheimer's disease, lives with spouse)**

> *"It was them (children) that said it to me. Them that noticed it (memory loss), they said it to us, they noticed it before I noticed it, they noticed it. It was them, then Deirdre (daughter) took over and she arranged everything then with the doctors"* **(018, Mrs. Buckley, female, 70 years, Alzheimer's disease, lives with spouse)**

In both the examples above, it was the respondents' children who first noticed symptoms and they quickly instigated their parents' access to diagnostic services. Mrs Buckley uses the words 'took over' to describe her children's involvement; it suggests a negative intervention and a loss of independence. Her husband had not noticed, or if he had he did not mention it to her, so their children told them. Phinney (2002: 335) argues that reactions of family members can indirectly or directly force awareness on the person living with dementia. Involvement from other family members could create negative relations. Interestingly in the case of Fr Hanrahan, it was his work colleagues who first noticed the fact that his behaviour had changed. He reacted quite strongly and felt that they and his family were ganging up on him:

> *"I found it very hard in fact, didn't, my own family and so on I felt that they were ganging up against me a bit (laughs)"* **(033, Fr. Hanrahan, male, 70 years, Alzheimer's disease, lives in religious community)**

Like several of the other men and women in the sample, Mrs Buckley initially ascribed the symptoms of dementia to 'old age':

> *"I actually didn't notice it, now I don't think I did and if I did I probably thought that it was just old age, I'm 78 you know"* **(018, Mrs. Buckley, female, 78 years, Alzheimer's disease, lives with spouse)**

However, after her daughter approached her and her husband again mentioning her forgetfulness and the doctor diagnosed Alzheimer's disease, Mrs Buckley became more aware of symptoms:

> *"...and I was saying I don't remember forgetting anything, I don't remember forgetting anything, sure I must have been, I must have been you know, but you don't notice it yourself, you don't. And eh now I do be watching things and I know when Martin says, do you remember such and such you know"* **(018, Mrs. Buckley, female, Alzheimer's disease, 78 years, lives with spouse)**

As the onset of dementia is often insidious, and its progression in the early stages can be *"very slow coming"* **(C032, Mrs. Barry, care-partner, spouse)**, it is understandable how relatives and people close to the person fail to recognise the early signs, passing off incidences of memory loss as just little slips:

> *"I passed that off as a bad night"* **(C032, Mrs. Barry care-partner, spouse)**

It was easy and acceptable to attribute the initial signs of memory and cognitive changes to older age (refer to section 5.3.1). This may partly explain why not all spouses noticed the early signs and in the three cases where spouses were the first to notice something was wrong, it was when other people were around or when they were in unfamiliar surroundings. The meaning of the person's situation changed and shifted. This could be based on fear of how the person was being viewed by others or looking at the person from another perspective or simple because their routine had been changed.

(ii) Early signs

I have already shown that not all respondents experienced symptomatic awareness or noticed their own memory loss/cognitive changes in the initial stages. For those respondents and their relatives who were aware or who were beginning to gain an awareness of changes, data analysis revealed a number of early signs and symptoms, signs which are commonly recognised as early signs of dementia in the literature (ASI, 2005; O'Shea and O'Reilly, 1999). However, the exploration here gives us further insight into the emotions experienced such as anger, frustration, embarrassment and fear that were connected with these commonly known symptoms of dementia. The most common sign reported by respondents was mislaying things, repeating questions or statements, non-memory related cognitive change (e.g. word-finding difficulties) and disorientation,

• For those who reported **mislaying things**, the most common items mislaid were purses, wallets, glasses and jewellery:

> *"I would be going into the bathroom for a shower or something like that and where is my bloody glasses, where's my bloody this thing you wouldn't know"* **(030, Mr. Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

For Mr Muprhy this was a nuisance. The emotional response for others to mislaying items included a sense of panic, frustration and displacement:

> *"Interviewer: Would you ever mislay things? That you put something down...? Respondent: Ah, that's very frequent, yeah. I have a purse that goes missing for ages, for hours (laughs) and then suddenly if I find it, it's up on the unit here... I got a bit panicky like I said, Jesus, Mary and Joseph I'm in my own home I should be able to find the thing"* **(010, Mrs. Curran, female, 74 years, Alzheimer's disease, lives with spouse)**

Hiding items was sometimes but not always connected to mislaying them. Some respondents hid valuable items (jewellery, money,

handbags) for safe-keeping and then had difficulty finding them. In one particular case the respondent did not mislay items but hid them:

> *"I'd leave my purse somewhere in the house, but I know where, I hid it you know (laughs). I have a whole lot of hiding places. That's when I first noticed it. And then I said here I better sort myself out here. I could spend hours looking for, looking for it you know, my credit card in it and oh my God (laughs). But eh now I have a place for things"* **(035, Mrs. Doherty, female, 76 years, vascular dementia, lives alone)**

After the onset of dementia, adopting a routine whereby important items were always left in the same place proved successful for many respondents (e.g. 'keys always go on the sideboard'). This reduced the frustration that mislaying items created and was a type of coping mechanism (coping mechanisms are examined in detail later in this chapter).

• Other early signs and symptoms of a dementia identified by care-partners included **repetition**:

> *"Talking, repeating the questions over and over again"* **(020, Mrs Watts, care-partner, spouse)**

> *"Kind of repeating himself a lot and then kind of saying to me that I never told him"* **(034, Mrs Doyle, care-partner, spouse)**

Thinking about how I would react to this type of repetition made me aware of how such questions can create much disharmony in social and family situations. This was very much evidenced in Mrs Doyle's case, particularly as she did not initially know that repetition was a symptom of dementia:

> *"I used to lose it then but now that I kind of know, I'm kind of biting my lip you know"* **(034, Mrs Doyle, care-partner, spouse)**

• Another indicator for people that they were experiencing something more serious than just age-related memory problems was new word-finding difficulties which were often difficult to cover-up:

> *"Interviewer: And how would you rate your memory would you say that it is good, bad or in between? Respondent: Not bad anyway, but emm, it's hard to know, I have no problems like really you know. But I get stuck like in conversation I will get stuck for words sometimes"* **(033, Fr Hanrahan, male, 70 years, Alzheimer's disease, lives in religious community)**

Fr Hanrahan did not equate his word-finding difficulties with cognitive and memory-related impairment but rather knew that he sometimes got stuck in conversation.

Another aspect of word-findings difficulties experienced by some was that of knowing the particular word or words but being unable to articulate them. This obviously had an adverse effect on communication patterns and affected the individual's morale:

> *"I can see it in my mind's eye the words, but I can't get it, it won't come out of my...."* **(017, Mr. Burns, male, 82 years, mixed Alzheimer's disease and vascular dementia, lives with spouse)**

This statement by Mr Burns, though short, gave me good insight into what it must be like for him. Everyone experiences instances where a word is on the tip of their tongue, where they can nearly see it.

• Becoming **disorientated in place** and **time** was yet another early sign of dementia experienced by some men and women. This was further broken down into getting lost in the local area, getting lost at home and disorientation in time and date.

- Getting lost in familiar surroundings such as the local area/neighbourhood:

> *"...because the evening was coming and it was growing darker like, you know. And I was saying sacred heart of Jesus where am I going to go. And [I] had to get out of the rain, I was soaked. So I'd seen a*

> *field and I, in the background I'd seen houses and I said will I go across that field, maybe I should be on that side. I walked the whole width of it and there was holes in the ground, it took me ages to get across the field. So, I was about ready to collapse when I recognised the road up there and I was oh God"* **(010, Mrs. Curran, female, 74 years, Alzheimer's disease, lives with spouse)**

Mrs Curran's account of this incident highlights the fear, frustration and panic experienced and the sheer physical exhaustion of someone trying to find one's way around when lost and disorientated.

Another care-partner reported that her mother started to get lost while out driving: *"getting lost in the car, literally"* **(C029, Ms Lynch, care-partner, daughter).** This was a signal to them that something was not right and pointed towards the gravity of the situation:

> *"If I have been out shopping or something and I come in and I might want to go into the bathroom. I'm going around opening the doors saying that's not the place. And this is out in the hall here. And I can't remember, saying God what did I come in here for"* **(010, Mrs. Curran, female, 74 years, Alzheimer's disease, lives with spouse)**

But for Mr Burn it was disorientation in time which made his wife more aware that he had a more serious problem:

> *"Interviewer: What kind of things does he forget? If he does forget things? Care-partner: Oh he does, you know he'll get up in the morning and he won't know for sure what day it is or am I going swimming today"* **(C017, Mrs Burns, care-partner, spouse)**

5.2.4 High and low levels of insight into the nature of dementia

It has already been stated that one cannot assume that people with an early stage dementia are unaware of changes in their memory

and cognition. Awareness of symptoms and changes in the lives as a result of having dementia is complex and may fluctuate from day to day. The nature of dementia is such that people may say that their memory is 'Okay' or good but then go into detail about events or incidences that have happened to them that clearly to the listener are beyond the features or characteristics of normal ageing. Being aware of changes is also not an indication that the person will be aware of the full nature of the illness. Phinney (2002a) argues that we need to examine how symptoms are lived and how people articulate these experiences to fully understand the lived experience of dementia. This also places great importance on engaging with people, using their life histories to examine awareness. For example, someone may appear to have no awareness yet be deeply affected by not being able to communicate as they used to or by getting lost in their local area. The feelings attached to such incidents cannot be discounted simply because the person is unaware of the illness or its prognosis.

Respondents articulated their awareness of the illness in different ways. Crudely these respondents and their awareness levels can be divided into two types namely (i) those with high levels of awareness/insight into the nature of the illness and (ii) those who had lower levels of this type of awareness/insight. From a careful analysis of the data it was found that respondents' awareness varied across, between and within individuals. Therefore, at times individual respondents did not display all high or low indicators.

The following characteristics were displayed by respondents who had what I categorise as a high level of awareness/insight into the nature of the illness:

i. The person was aware of the symptomatic effect of the illness e.g. why they found things different or difficult. For instance: *"I was a good reader but I haven't got the attention now to do it"* **(030, Mr Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

ii. They reported a high degree of memory loss (they did not refer to it as normal ageing, or little slips etc.) and noted its deteriorating effects. For example: *"Well it (memory) was getting bad a long time and I didn't know. In the last, in the last five years or so I find it very bad"* **(036, Mr Moore, male, 93 years, mixed Alzheimer's disease and vascular dementia, lives alone)**

iii. They identified with and talked openly about their diagnosis: *"Interviewer: So you got on Okay up in -------- hospital? Respondent: Professor is pleased. Interviewer: Good. Respondent: Yeah he is and he said my, my kind of Alzheimer's, he said and he had it all in front of him looking back"* **(004, Mrs Beattie, female, 67 years, Alzheimer's disease, lives alone))**

iv. They implemented strategic coping mechanisms (see section 5.4)

v. They were aware of how others were affected by their illness: *"Martin and he, I know must be feeling awful but he's taking it (her dementia) in his stride"* **(018 Mrs Buckley, 78 years, Alzheimer's disease, lives with spouse)**

The following are characteristics of respondents who displayed a lower level of awareness of the nature of the illness:

i. They felt/thought that their memory would return to normal, as is evident in the following excerpt: *"Interviewer: Do you think in time your memory problem will return to normal? Respondent: I think so, yeah, I think so yeah"* **(010, Mrs Curran, female, 74 years, Alzheimer's disease, lives with spouse).** However, in retrospect this question was leading. I do not think that Mrs Curran would have stated that she felt her memory would return to normal if I had not suggested it.

ii. They saw their memory and cognitive decline as a normal part of the ageing process. For instance: *"Care-partner: But she is now, she's more forgetful now that she was three years ago. Respondent: But we're not getting younger*

man" **(038, Mrs Gannon, female, 62 years, Alzheimer's disease, lives with spouse)**

iii. They felt that their memory would not get any worse, as the following statement indicates: *"Interviewer: And do you ever think it will return to normal? Respondent: I think I am coming a bit back to normal. Well I don't know if it's like this, but I have improved now"* **(035, Mrs Doherty, female, 76 years, vascular dementia, lives alone)**

iv. They did not feel/think that any changes in their cognition significantly affected their ability to do things (however in the early stages this is often the case): *"I'm very independent"* **(038, Mrs Gannon, female, 62 years, Alzheimer's disease, lives with spouse and daughter)**

v. They saw other family members' (specifically care-partner's) memory as the same or worse than their own: *"Well I find it's not as bad, I do catch him out when he does forget something. I do be delighted, I do say you told me that already"* **(038, Mrs Gannon, female, 62, Alzheimer's disease, lives with spouse and daughter)**

vi. Showing no anger or frustration when talking about memory and accepting completely other people's explanations for circumstance and situation is another sign of low awareness e.g. Mr Watt's accepted that he no longer drove based on his wife's explanation that the insurance was up.

Some of these themes will be revisited in the psychological responses section of this chapter, as many of the themes identified as low levels of awareness can be attributed to psychological coping mechanisms.

5.2.5 Section summary

Findings on awareness presented in this thesis concur with other empirical research on the topic, where it has been demonstrated that people living with dementia particularly those in the early stages can have high levels of awareness (Clare, 2002; Cotrell, 1997; Dröes, 2007; Froggart, 1988; Howorth and Saper, 2003; Mullen et al, 1996;

Phinney, Wallhagen and Sands, 2002). Unawareness is a complex phenomenon. Some may be unaware because of the memory and cognitive problem itself but others may be unaware simply because their next of kin, friends and acquaintances deny there is anything wrong and therefore feed into their own hopes and wishes. Indeed family members may actively impede their seeking out a diagnosis by failing to talk about the issues and by failing to face up to the symptoms themselves. People can also demonstrate insight into their symptoms but not necessarily into the nature of their dementia. This view supports Killick and Allan's (2001) belief that we need to broaden our conceptualisation of awareness; viewing it as more than just cognitive conceptualisation. Awareness can also fluctuate and vary across and within people living with dementia. Findings show that psychological responses and reactions to dementia can not be controlled for by simply examining organic (e.g. neurological) reasons for unawareness (Mullen et al, 1996: 649), every person is unique and they respond in different ways depending on their own circumstances, for example where there is potential for 'motivated denial' of the illness e.g. Mr Doyle's case.

Findings show that we cannot solely depend on quantitative approaches to gain any real insight into awareness of dementia as qualitative data analysis yielded different results when compared with findings using a quantitative measure. This finding is similar to Phinney's (2002b: 331) argument that awareness for people living with dementia is a way of being in the world, an expression of the lived experience and may not be articulated through narrative. Therefore, examining how people react, interact and talk about their lives generally can tell us more about awareness than asking someone to articulate the experience of dementia specifically. For example, findings from this research showed how questions raised using Likert scales showed a positive bias with people in general rating their memory as being considerably better than how it actually was when they spoke about it in a more open ended way. This is also a common finding in the use of Likert scales with people with intellectual disabilities (Hartley and MacLean, 2006). They provide a

limited insight into the lived experience as a result. Following these questions by qualitative data gathering created a more holistic picture of the experience.

From data analysis it was found that only one respondent, Mr Watts, had no awareness of his symptoms or the nature of his illness, and interestingly he did not react negatively or angrily when I asked him about his memory. His inclusion in the sample was useful as it has allowed a comparison to be made between his situation and that of others who were more aware of their symptoms and their manifestation and who sometimes reacted more adversely in their discussions with me about the issues. Mr Watts for example failed to show any signs of motivated denial or covering up of symptoms, as other respondents had when they spoke about their memory. Others reported having a good memory but later mentioned symptomatic effects of memory and cognitive disability whereas this was not the case for Mr Watts.

Several of these men and women had noticed the early signs of memory and cognitive changes themselves. For those who were married, their spouses had by and large also been instrumental in recognising the changes. However, physical proximity to the person living with dementia, i.e. co-habiting, was not always a predictor of awareness of dementia or significant memory/cognitive change, as changes in cognition were often passed off by spouses as normal ageing or in their view had arisen as a result of a bad day/night. Social constructionism is a useful lens through which to consider these findings where the meaning of the person's changed abilities/cognition became more significant when the person's abilities were viewed from another's perspective. The reality of the situation for care-partners was often constructed in the process of interaction with others.

The main early signs and symptoms of dementia identified by the sample were mislaying and hiding items/things, repetition, disorientation in time and place and non-memory related cognitive

changes. These findings are similar to categorisations of symptoms of the early stages found elsewhere. However, by inquiring in a person-centred way about the early signs and symptoms I felt that I gained a clearer idea of what experiencing the symptoms meant for the person. In other words, their stories were being told as they experienced them and were no longer abstract but alive. Reactions by respondents to these early symptoms often had real and limiting consequences. For example, Mrs Curran no longer went out alone as a result of an earlier experience where she got lost in her own locale. She had effectively become housebound. This had potential for causing stress in her relationship with her husband, as she was relying on him more.

Before moving on to the next section I want to return to the model of awareness as outlined in Figure 5.1. Reporting on levels of awareness cannot be solely based on people stating that they have dementia/Alzheimer's disease, as often there are reasons they do not or cannot do this. Therefore we must look at how the person talks about their memory/cognition and recent changes they have noticed in their abilities. The meanings people attribute to these changes are sometimes based on how others talk about them and how others view them. This is in line with Kitwood's (1997) person-centred approach to dementia and with social constructionism. De-constructing awareness, in dementia, one considers how the person conceptualises the course of the changes experienced. Do they know it will get worse; do they know that sometimes their memory will be better than other times; and do they accept that what others say about their changed memory/cognition despite their failing to notice changes themselves? Sometimes it takes others to note changes and for the person to begin to notice themselves.

5.3 Responses to the Onset of Dementia

This section details the responses and reactions respondents had to the changes they experienced to their memory and cognition as a result of their dementia. Whilst the previous section on awareness

yielded some insights into how respondents made sense of their dementia, the section to follow will further develop this issue. The key themes which emerged from the in-depth discussion on responses to the onset of the illness were normalisation, self-blame and changing roles. Emotional responses emerging from the data include (i) anxiety and frustration, (ii) acceptance, (iii) fears, (iv) sadness, (v) lack of confidence and (vi) moving towards an understanding. This section also examines these men and women's social responses to having dementia, embedded in social constructionism as discussed under the headings of improving relations, impact of others, telling people and talking about their dementia. The chapter concludes by examining other ways respondents coped with the onset and progression of dementia.

5.3.1 Making Sense of dementia/memory problem

Respondents made sense of their memory problem in varying ways. Several implemented different strategies to adapt to what was happening to them. Data analysis led to three broad strategies emerging namely normalisation, self-blame and changing roles.

(i) Normalisation

Many respondents considered their memory loss as a normal part of the ageing process and cognitive and memory loss was seen as something that could be expected in older age and something they should cope with as a consequence of ageing. These findings are in keeping with the literature on the lived experience of dementia (MacQuarrie, 2006, Gillies, 2000). Stansell (2002: 225) states that people with Alzheimer's disease do not define themselves by losses but they tend to normalise what is happening and strive to continue doing things that are important to them. Viewing memory and cognitive change as a normal part of ageing reduces the person's perceived level of disability and the full impact of having dementia. By normalising their symptoms they were not setting themselves apart from others the way in which they would be if they had a deteriorating illness; this is less stigmatising. Findings show that this was

an approach adopted often by both the person diagnosed and by those around that person.

There was an expectation of imperfection and deficit in older age expressed by respondents, suggesting an inherent ageism in our society. Negative references were made about ageing and becoming old:

> *"Interviewer: And did anyone ever give a reason why your memory was changing? Respondent: I suppose age-wise, you can't expect to be perfect in every way. Well I didn't notice it myself now"* **(041, Mrs. Martin, female, 77 years, Alzheimer's disease, lives with spouse)**

Other people helped to reinforce respondent's normalisation of experienced changes. I think this was an attempt to reduce possible embarrassment and make respondents feel more at ease or it was used as a coping mechanism by care-partners and by significant others. Again this suggests that other people may have a big fear of dementia and see it as stigmatizing. Attributing the symptoms to the normal ageing process may have helped to normalise the changes observed. Mrs Curran's sisters spoke about their own (physical) impairments to reassure and ensure her that she was not different or out of place:

> *"Well I'm always with my sisters you know that way. And sure, they all say 'ah don't be worrying about that sure I'm deaf and I'm the other one has something else', you know. You just have to laugh these things off, you know"* **(010, Mrs. Curran, female, 74 years, Alzheimer's disease, lives with spouse)**

Comparing oneself to others promoted a positive self-perception by making light of the problem. Clare (2002a: 145) asserts that people with dementia can make selective comparisons to people that they perceive are worse off than themselves. People living with dementia interviewed for this thesis also implemented the same strategy. Mrs

Gannon did not want to categorise herself as different, she felt her forgetting was common for her age group even though she was only in her early sixties and the youngest person in the sample:

> *"Ah yeah, I would forget things, but when you get to this age you do forget things. Everyone forgets"* **(038, Mrs. Gannon, female, 62 years, Alzheimer's disease, lives with spouse)**

A common theme was likening oneself to others; finding common ground with others or a shared experience. Seeking a shared experience also provided a meaning to changes that were being experienced.

(ii) Self-blame

Respondents often chastised themselves for forgetting things and blamed themselves for their memory decline. They felt it was their fault that their memory was starting to change, sometimes ascribing their memory problem to laziness:

> *"I read the papers, I used to read a lot and I used to love knitting and ehhh sewing. But I'm afraid I have got very lazy"* **(029, Mrs. Lynch, female, 87 years, Alzheimer's disease, lives alone)**

This also reflects an attempt to make sense of changes experienced by linking them to altered habits or patterns of behaviour.

Mr Barry talked about avoiding doing things presumably lest in the event of his attempting to do the task he might fail:

> *"It's not that I'm not able to do it, I just don't do it."* **(032, Mr. Barry, male, 79 years, mixed Alzheimer's disease and vascular dementia, lives with spouse)**

In line with this concept of self-blame, care-partners, it could be argued, also had a tendency to blame their relative. Some for example reflected on their relative's lack of activity and how they felt this contributed to and exacerbated their impairment:

> *"He won't go out for a walk around the block, he's got a bit lazy...he doesn't have to remember"* **(C039, Mrs. Callaghan, care-partner, spouse)**

This quote from Mrs Callaghan shows how she is attributing some meaning to what is happening to her husband.

Others blamed themselves for not paying enough attention to what was happening around them or for not listening to what was being said and pointed to their being actively responsible for remembering things because of their inattention.

> *"Yeah, I suppose I do, yeah. It's a lack of attention, I would think more than anything else. Somebody's talking and I'm only listening with half an ear, that type of a way"* **(034, Mr. Doyle, male, 76 years, Alzheimer's disease, lives with spouse)**

> *"Okay I might have talked to somebody and maybe I might, then when they asked me the next day I mightn't remember all of it, I would know who I've met it's not total memory loss. Possibly a lot of it is my own fault, literally, even though he was talking to me I wasn't listening, that type of a way"* **(033, Fr. Hanrahan, male, 70 years, Alzheimer's disease, lives in a religious community)**

Mr Doyle explained his failings in his memory by arguing that he was careless in his approach to situations:

> *"I wouldn't say its (memory) bad or it's good really. I'm a bit careless really, my memory is alright, I remember enough anyway let's put it that way"* **(034, Mr. Doyle, male, 76 years, Alzheimer's disease, lives with spouse)**

Fr Hanrahan attributed his problems to the recent changes in his life hence, including the fact that his routine had been disrupted:

> *"Interviewer: And what kind of things do you forget? You mentioned appointments and dates a little bit. Respondent: Yeah I would be careless I'd say anyway you know. Well, when you're on a job when you're, you're pinned down you know, you're exact you know and you have your things, you write them down, but like with me I, I tend, I'd make some arrangement about tomorrow or the day after and I might forget. But I'm not bad that way, I'm not bad at the same time. Yeah I would be careless I'd say anyway you know"* **(033, Fr. Hanrahan, male, 70 years, Alzheimer's disease, lives in religious community)**

Making sense of the symptoms of dementia was also influenced by economic, social, and cultural factors and by the individual's earlier life experiences as Mrs Lynch's testimony demonstrates:

> *"No, ehh, you know we were always emmm, when we were growing up we always had to be doing things, we always had to have an interest in things. So I mean there was never a time when you kind of got bored there was always something to do. As my mother used to say the devil has plenty of work for idle hands"* **(029, Mrs Lynch, female, 87 years, Alzheimer's disease, lives alone)**

Linking Mrs Lynch's comment here back to forgetfulness due to laziness or inattention, several respondents seemed to conceive of their memory difficulties as resulting from not being busy and active or as Fr Hanrahan suggested not being at work.

(iii) Changing roles

In the same way as Fr Hanrahan attributed the cognitive changes he noted to recent events in his life, others also used similar strategies commenting on how their work and domestic roles had changed and that this could have led to their changed behaviour:

> *"I think he went down when he finished all the mills (work) and all that"* **(C039, Mrs. Callaghan, spouse care-partner)**

Others spoke about how the absence of contact with others had led to memory loss. Mrs Doherty had raised a large family and now her social contact had decreased and her role had changed:

> *"When you raise seven children and then you're left on your own it gets a bit, it's a big shock...You see if you're living alone and you're not interacting with people you're inclined to go a bit ...(trails off)"* **(35, Mrs. Doherty, female, 76 years, vascular dementia, lives alone)**

Mrs Martin also felt that a lack of contact with other people made her self-conscious when talking to people:

> *"Well it's I don't find it (memory) that it's low or anything like that you know. But like when you do sort of stop meeting people and all that you can't sort of say gosh what'll I talk about you know. Instead of just being yourself... I know as you progress and you're off all the things you used to do that's what keeps people in touch, is doing the work that they do you know"* **(041, Mrs. Martin, female, 77 years, Alzheimer's disease, lives with spouse)**

Mrs Martin is self-conscious in front of other people; she does not know what to say. She states that she does not know how to be herself. Although she attributes this to a general lack of social contact, I would also suggest that it is because she feels less confident and possibly does not want to be judged by others.

5.3.2 Emotional responses to dementia

Respondents reported both positive and negative responses to their awareness of having dementia. Aspects of responses were often based on emotions; the following section refers to these emotional responses respondents reported when they were coming to terms with changes.

(i) Anxiety

Anxiety was a common emotion expressed by many of the men and women in this sample, particularly when they thought about their dementia/memory and what the future held for them:

> *"Ehh, anxious. You know kind of, I hate when I forget"* **(024, Mrs. Griffin, female, 75 years, Alzheimer's disease, lives with spouse)**

> *"I feel, sometimes I kind of get a bit panicky, where I'll say I won't even be able to talk to anyone"* **(010, Mrs. Curran, female, 74 years, Alzheimer's disease, lives with spouse)**

Interestingly, Mrs Curran reported having a good memory when directly asked yet like others when this matter was further investigated she spoke openly about the anxieties she felt at not being able to do things. However, failure to do the things she was once accustomed to doing did not in her view appear to be related to her memory.

The fear and despair some people felt about what was happening to them because of their dementia was openly referred to by Mrs Beattie:

> *"Well with this (points to head, referring to Alzheimer's) kind of Alzheimer's it is very like frightening. Not all the time, but sometimes, very frightening. Very hopelessness, feeling like, you know that way"* **(004, Mrs Beattie, female, 67 years, Alzheimer's disease, lives alone)**

Mrs Beattie during our interviews was a very upbeat person, she was warm, friendly and open (see Appendix G for full transcript). For the most part, she kept any anxieties she may have felt about the illness under wraps.

Memory loss also created confusion, where the person felt muddled and not in control. I use the words not in control here, as my own interpretation of being 'in a ball' is when a person is anxious or unsure or confused and not in control:

> *"I knew you were coming and I forgot it, you know that sort of way, just things don't register as fast as they used to you know. I'd be all in a ball like"* **(024, Mrs. Griffin, female, 75 years, Alzheimer's disease, lives with spouse)**

(ii) Future fears

I asked respondents and their care-partners directly if they had any fears for the future. One could argue that this in itself is a leading question but it was asked in order to discover whether respondents knew of their prognosis and were aware how their memory and cognitive disability might further progress. Interestingly this was a useful question which elicited some of the most profound insights from respondents. The question led some of these men and women to ask questions of me about the illness. I felt somewhat out of my depth as a result. I did not have the answers they were looking for and it was in conflict with my role as a researcher. I addressed it as best I could by giving them contact details for other organisations and encouraging them to go their GP or the outpatient clinic with their concerns. The question on fears for the future gave me huge insight into their understanding of what was happening to them where before this question was posed they either chose not to or perhaps were unable to talk about these issues in any way.

The most common future fear respondents and their care-partners had was that of going into hospital or into a nursing home:

> *"I just wish that I wouldn't like to have to go into a place where you would have to be minded"* **(004, Mrs. Beattie, female, 67 years, Alzheimer's disease, lives alone)**

> *"I don't want him to be moved to hospital, I wouldn't put him in hospital... I only hope to Christ that he never has to go anywhere, you know what I mean that's my only wish that he never does that he ends*

> *his days here with me and that's it"* **(C032, Mrs. Barry, care-partner, spouse)**

This fear of nursing home admission (a fear of many older people, not only those with dementia, and well documented in the literature (Garavan et al, 2001)) was also related to a concern about deterioration and loss of independence and further decline:

> *"I'd hate not to know people... Well the only one [fear] I have is that if this multiplies. Will it?"* **(018, Mrs. Buckley, female, 78 years, Alzheimer's disease, lives with spouse)**

> *"Interviewer: And do you have any future fears? Respondent: Fear that I wouldn't be able to cope on my own"* **(004, Mrs. Beattie, female, 67 years, Alzheimer's disease, lives alone)**

For Mrs Buckley there was much uncertainty, a fear of the future and a sense of being aware but unsure about what would happen:

> *"Naturally I wish I wasn't going to be what it may turn out to be, I know what it is but how bad does it get?"* **(018, Mrs. Buckley, female, 78 years, Alzheimer's disease, lives with spouse)**

> *"I feel sometimes that emm, oh, it makes me anxious at times you know about myself and before I used to get anxious, forget it you know. But emm, I'm now more realising that this is what, this is the future you know, what am I going to do? But emm, other than that like emm, it's, it's something that's going to happen and I can't stop it"* **(024, Mrs. Griffin, female, 75 years, Alzheimer's disease, lives with spouse)**

Mrs Griffin's statement, "this is the future", suggests that she has realised that her memory/cognitive changes are not curable and will never go away. Her words reflect a sadness but also a sense of

acceptance and reconciliation. There is a strong plea for help in this commentary – "what am I going to do"?

I found this question on future a difficult one to ask. I felt that it might imply that respondents should be afraid for their future. Reponses to it were often emotional. However, where respondents engaged with the question (as shown above) they showed a deeper level of understanding than I had initially thought, and I also realised that I was not asking them to think about anything that they had not thought about before. However, for many, it may have been the first time they articulated it. In Mrs Buckley's case it certainly was, as she mentioned she did not discuss her dementia with anyone, yet she had great insight.

(iii) Frustration

Frustration and annoyance were other emotional responses to changes experienced as a result of dementia. Mrs Lynch summed up the frustration she felt at having a memory and cognitive disability:

> *"By the time you make up to do anything, ehmm, to put your thoughts into actions, by the time that stage comes it's gone... well what did I start this for you know"* **(029, Mrs. Lynch, female, 87 years, Alzheimer's disease, lives alone)**

> *"Interviewer: How does it make you feel when you forget things? Respondent: I would be annoyed with myself"* **(32, Mr. Barry, male, 79 years, mixed Alzheimer disease and vascular dementia, lives with spouse)**

Despite having short-term memory problems some respondents maintained a very good long-term memory. At times this was a source of frustration for them when they tried to understand and make sense of these changes:

> *"Ehh, well I can remember things that happened fifty years ago but I couldn't remember what was happening yesterday, if you know what I mean"* **(020,**

Mr Watts, male, 82 years, Alzheimer's disease, lives with spouse)

"Interviewer: So can you tell me a little bit about your memory? How it is? Respondent: Emm, I can, I can go back to footballers, club footballers that sort of thing you know, I can remember the wars and all that sort of thing" **(030, Mr Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

(iv) Understanding and acceptance

As I mentioned at the beginning of this section emotional responses on the part of these men and women to their dementia were not all negative. Often once recognition and the immediate response to the illness had occurred many respondents, amongst those who manifested awareness, once they recognised the reality of their situation, began to understand and accept what was happening:

"I do forget and I have to accept it" and *"if I forget I forget (laugh)"* **(024, Mrs. Griffin, female, 75 years, Alzheimer's disease, lives with spouse)**

"Well there's no use saying getting rid of this, Alzheimer's" **(018, Mrs. Buckley, female, 78 years, Alzheimer's disease, lives with spouse)**

"I find when you understand it (dementia), like, that would be for me anyway, that this, that it's Okay, something, this is happening to you, it's part of, of, of the illness or it's something else?" **(004, Mrs. Beattie, female, 67 years, Alzheimer's disease, lives alone)**

Mrs Beattie's quote shows how once she understood what was happening, she may have been marginally relieved for she no longer had to feel at fault or to blame herself and having dementia meant that she did not need to be embarrassed, Mrs Griffin's quote above also shows how the frustration dissipates once acceptance occurs. This type of acceptance as reflected in these findings is also

identified in the literature as a way of positively coping with dementia (Harris and Durkin, 2002).

Navigating through un-chartered territory was a challenge but once one became familiar with the new terrain, finding one's way became a little easier. Part of acceptance was therefore getting used to a new situation:

> *"I think he's [husband] got used to it now, as I had to myself"* **(018, Mrs. Buckley, female, Alzheimer's disease, 78 years, lives with spouse)**

Adapting to their situation and accepting it was usually described in positive terms. There seemed to be a connection between acceptance and remaining positive, getting on with life rather than dwelling negatively on their situation, taking a pragmatic approach:

> *"I don't feel that anything is going to change you know, sure I just get along with it. Sometimes I'm not as bad as other times, you know"* **(010, Mrs. Curran, female, 74 years, Alzheimer's disease, lives with spouse)**

When asked about his quality of life, Mr Murphy said:

> *"Quite good, apart from what's wrong with me now you know, that's a fact and you're not going to change that. It's pretty good, pretty good"* **(030, Mr. Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

In analysing these data it would have been easy for me to focus only on the negative aspects of the disability as clearly from an outsider's point of view dementia is a cruel and relentless illness. However, in most cases respondents were getting on with their lives and coping adequately and admirably with their changing worlds. Some, as Mr Murphy's testament demonstrates, were very active and making valuable contributions in their locale. Mr Murphy had a relatively normal life. Similarly to Mr Doyle who was mentioned earlier he had recently remarried and was estranged from his children from his first marriage and he had also recently retired. Mr Murphy differs from Mr Doyle on one key issue as he spoke openly about having Alzheimer's

disease, he found that as time was going by he was starting to get lonely for the first time in his life. He still recognised that his life was 'pretty good, pretty good', and my reading of it, where he met up with his friends twice a week in the pub, ran out to his neighbour during one of our interviews to lend her some garden equipment after taking a phone call from her, showed me that it was indeed good.

Many care-partners also appeared to go through a process of acceptance. This acceptance of the illness and its symptoms came with an improved understanding of what was happening and seemed to help people to cope more successfully as a result:

> *"Interviewer: Do you ever feel embarrassed by Desmond? Care-partner: Well I have but not any more, whatever you like to make of that. Interviewer: And why not any more? Care-partner: Because I accept it now and I expect everyone else to accept it as well you know"* **(C017, Mrs. Burns, care-partner, spouse)**

This quote from Mrs Burns, it could be argued, reflects the whole issue of the stigma of dementia in our society. Kitwood (1993) and Sterin (2002) talk about the stigma of being labelled with dementia. However, Mrs Burns's words challenge this, as once she knew her husband's diagnosis; it seems that having a dementia legitimated how his behaviour had change and helped to explain to others why he was acting the way he was.

For some care-partners, attributing their loved one's memory disability to normal ageing made accepting it easier:

> *"You know an awful lot of it is, maybe that's a very uneducated thing to say, but an awful lot of it is old age, you can't, you just get to that stage I presume"* **(C041, Mr. Martin, care-partner, spouse)**

Amongst those men and women who accepted their dementia several were resigned to the absence of effective treatments interventions or the prospects of recovery:

> *"I don't feel that anything is going to change you know, sure I just get along with it. Sometimes I'm not as bad as other times, you know"* **(010, Mrs. Curran, female, 74 years, Alzheimer's disease, lives with spouse)**

> *"I'm annoyed but I don't get, I just say, there's nothing I can do about it"* **(018, Mrs. Buckley, female, 78 years, Alzheimer's disease, lives with spouse)**

Some drew on wisdom imparted by other family members to help them accept the changes experienced and to enable them carry on:

> *"My mother used to say the Lord makes the back for the burden... the Lord makes the back for the burden"* **(035, Mrs. Doherty, female, 76 years, vascular dementia, lives alone)**

(v) Sadness

Some respondents revealed a sense of sadness and anger about having a dementia and felt grief over the losses they were experiencing:

> *"Emm, it annoys me. Yeah I get emm, I'm sad about it, I, I, as I say I try to cover it up"* **(024, Mrs. Griffin, female, 75 years, Alzheimer's disease, lives with spouse)**

There were also feelings of regret conveyed about the onset of the illness and a wish that it had never happened:

> *"I wish that, I wasn't, that it wouldn't have happened, that's what I wish"* **(004, Mrs. Beattie, female, 67 years, Alzheimer's disease, lives alone)**

(vi) Effect on confidence

Amongst those who reported a loss of confidence, the data revealed the types of issues which caused respondents to lose confidence in themselves, such as fear and anxiety about going out and uncertainty about making decisions:

> *"No I don't know what it is, whether it is I'm afraid I'd lose my bearings, you know of where I was. How do I get back"* **(029, Mrs. Lynch, female, 87 years, Alzheimer's disease, lives alone)**

> *"I'm not, I prefer, I don't like making decisions as well because if I do and then I don't feel, if I feel all over the place and I don't want to go, you know. I don't, I don't want to be there that I couldn't cope"* **(004, Mrs. Beattie, female, 67 years, Alzheimer's disease, lives alone)**

Mrs Beattie was uncertain about the future and her inability to predict good days and bad days. As a consequence she had no confidence to make decisions which might involve a level of commitment. She also did not want to let other people down by not being able to follow through with commitments. This can explain why people often withdraw after the onset of dementia (see chapter six for further discussion on withdrawal).

For Mr Burns, it was the changes brought about by his dementia which caused him to lose his confidence:

> *"Interviewer: Confidence, would you have a lot? Respondent: Confidence, I would be 'leave me alone'. Interviewer: So you're not very confident? Respondent: Not with the way I am now. Interviewer: And would you have been confident before? Respondent: Ah yeah"* **(017, Mr Burns, male, 82 years, mixed Alzheimer's disease and vascular dementia, lives with spouse)**

Respondents were also asked to rate their confidence levels using a five-point Likert scale. I applied the same rationale for including this structured question as I did for the question on awareness. I wanted to compare quantitative and qualitative measures. Table 5.2 shows that six respondents reported their confidence as 'Okay' (Mr Watts, Mrs Griffin, Fr Hanrahan, Mr Doyle, Mr Callaghan and Mrs Martin). Another six reported having high levels of confidence (Mr Burke, Mrs Lynch, Mr Murphy, Mr Barry, Mrs Doherty and Mrs Gannon) and five said that they lacked confidence or that their confidence levels were low (Mrs Beattie, Mrs Curran, Mr Burns, Mrs Buckley and Mr Moore). Three of the four people (Mrs Buckley, Mr Moore and Mrs Beattie) who reported having a bad memory in the question presented earlier on self-reported memory, also reported having a lack of confidence. Interestingly these three respondents all spoke openly about their diagnosis of dementia. This suggests a correlation between level of confidence and knowledge or awareness of diagnosis. The other respondent who earlier reported having a bad memory problem was Mr Murphy who reported a high level of confidence.

Table 5.2: Self-reported level of confidence

Self-rating of confidence ('How would you rate you self-esteem/confidence, now? Very low, low, neither high nor low, high or very high?)	Very low = 0 Low = 5 Neither high nor low= 6 High = 6 Very high = 0 No comment = 0

This Likert scale data therefore showed that most respondents claimed to feel quite confident. I followed this question through with more unstructured questions about confidence and self-esteem, which provided a deeper understanding of what having or not having confidence meant to these people experiencing the early stages of dementia:

> *"Interviewer: Would you be confident? Respondent: Do I feel confident? Interviewer: Yes. Respondent: Yes I think I do, yeah I think I do. Interviewer: That hasn't changed? Respondent: When I say a thing I*

mean it" **(029, Mrs Lynch, female, 87 years, Alzheimer's disease, lives alone)**

Mrs Lynch comes across as somewhat defensive when I probed this issue further. My mentioning a change in confidence instigated this, suggesting that she is aware that a change has occurred.

Another respondent, Mrs Doherty, felt that she needed to hold on to her confidence or she would just give up:

"Sure God if you loose your confidence you may as well go to bed" **(035, Mrs Doherty, female, 76 years, vascular dementia, lives alone)**

Confidence was therefore very important to her as it was related to independence and the desire to live.

Confidence seemed to be associated with family and work roles. For example, doing things at home or being in paid employment gave respondents confidence. For some, retirement caused confidence levels to diminish:

"Interviewer: And how would you rate your confidence and self-esteem now? Respondent: Eh, I don't need much confidence now because I'm doing very, very, very, very little now" **(020, Mr Watts, male, 82 years, Alzheimer's disease, lives with spouse)**

Confidence was also related to doing activities successfully, at present or in the past:

"Interviewer: Would you say you are a confident person? Respondent: Yes. Interviewer: Would you say you have always been a confident person? Respondent: Well em, yes, yes I would, starting off with cattle when I was quite young, animals, fishing and all those sort of things and then going all around Ireland (for his work) from various areas and all those areas were completely different" **(023, Mr Burke, male, 78 years, Alzheimer's disease, lives with spouse)**

(vii) Feeling stupid

Some respondents reported that their memory problems made them feel stupid and mentioned how other people contributed this to their low self-esteem. Mr Callaghan felt stupid, like 'the village idiot'. He felt under scrutiny particularly when he was being medically assessed and when others reaffirmed the negative image he had of himself:

> *"I'm the village, I'm the village idiot so I let it pass but that's some of your testers would have to make sure some judicious announcement about it, how do you expect a guy's future when he's being studied, suspected fat head, can't remember his own name"* **(039, Mr. Callaghan, male, 82 years, mixed Alzheimer's disease and vascular dementia, lives with spouse)**

His case is interesting, as the processes involved in his formal cognitive assessment and neuropsychological testing, made him feel stupid. The judgement that he felt was being made based on these questions made him feel stupid. Preston, Marshall and Bucks (2007: 133) call this 'self as substandard', where people identify themselves with negative identities as a result of having dementia.

Another respondent spoke about how a friend deliberately let him stumble over words without assisting him:

> *"Interviewer: He wouldn't help you. Respondent: No. Interviewer: How does that make you feel? Respondent: Pardon. Interviewer: How does that make you feel? Respondent: A twit"* **(017, Mr. Burns, male, mixed Alzheimer's disease and vascular dementia, 82 years, lives with spouse)**

Both these quotes illustrate how other people affected the lived experience of dementia. These two men were made to feel stupid as a result of interactions with others, in one case it was with health service professionals and in the other case it was with friends.

(viii) Feeling hopeful

Curiously analysis showed that when respondents understood the causes and consequences of their illness they were more likely to

respond with feelings of hope and optimism. Some expressed hope that there would be improvements in treatments or even a cure and demonstrated much faith in the medical profession:

> *"Interviewer: Do you have any future fears about your memory problem? Respondent: No I don't because I think as it goes on the medical profession is getting better all the time and they know how to treat their patients, they're very good and very patient themselves for some people"* **(010, Mrs. Curran, female, 74 years, Alzheimer's disease, lives with spouse)**

Others expressed a desire to maintain their current level of ability, realising that there had been changes but hoping that they would plateau and not deteriorate further:

> *"We will just have to wait and see. But I hope to stay here (points to head) as long as I can"* **(018, Mrs. Buckley, female, 70 years, Alzheimer's disease, lives with spouse)**

(ix) Effect on others

A common theme running through the qualitative data was respondents' awareness of how what was happening to them affected others. Some who retained insight felt guilty about becoming a burden on a loved one:

> *"I felt sorry for asking him that (the respondent had asked her husband to leave the room before we continued with the interview), but he's all right, he was very upset though at the time (of diagnosis). It was an ordeal I think it was. He never said anything but I knew by him, he was being as nice as he could you know. But I think he's got used to it now, as I had to myself"* **(018, Mrs. Buckley, female, 78 years, Alzheimer's disease, lives with spouse)**

Mrs Buckley, who obviously had good insight, felt sorry for her husband, coming to terms with and dealing with her disability in a similar way as she had to. Her transcript provides a good example of

how a relationship-centred approach acknowledges the impact dementia has on all stakeholders, not just the person living with dementia. There was also a hint in this quote that they would face the journey into dementia together.

It has already been mentioned that respondents did not want to be a burden on others. This may explain why many did not want to talk to others about their situation:

> *"Interviewer: And would you openly talk to people about your memory. Respondent: No. I don't bother, they have their own business"* **(017, Mr. Burns, male, 82 years, mixed Alzheimer's disease and vascular dementia, lives with spouse)**

> *"Interviewer: Would you say you lean a lot on Vicki (spouse)? Respondent: Ah you do, she has her things to do and I'm taking that away from her you know (respondent becomes upset), more or less...When you marry, don't marry a guy like me. Interviewer: Why not? Respondent: You'd be stumbling over the table and chairs looking for words"* **(017, Mr. Burns, male, 82 years, mixed Alzheimer's disease and vascular dementia, lives with spouse)**

Burns and Mr Barry both leaned on their wives for support. Mr Burns felt guilty about this. He also felt socially awkward and the quote reveals his awareness of his disabilities. However in Mr Barry's case, the same sense of guilt did not emerge bur rather he revered his wife for her tolerance and coping skills:

> *"She's brilliant though, I think if the thing was on the other foot I couldn't stick it out the way she does"* **(032, Mr. Barry, male, 79 years, mixed Alzheimer's disease and vascular dementia, lives with spouse)**

Most care-partners did not talk openly with their relatives about their dementia. In one unusual case a care-partner, Mrs Barry mentioned that she was unsure whether she should talk to her husband about his diagnosis. It was a concern at the time of the interview as there were

several programmes about dementia and Alzheimer's disease on the television and she was worried these might upset him:

> *"Care-partner: You see, this is the problem I have Emer, you know there's been a lot on the television [abut dementia]. I get so embarrassed for him, will I change it? What'll I do, that's the only thing, I can't talk to Seamus about it. Interviewer: Does anybody talk to him about it? Care-partner: No, he doesn't say, he'd talk to you but I say 'God you asked me that before', 'Did I?' Next thing he'd say 'what day did you say it was?' (Laughs) That kind of thing, you know. That's one question I'd be loving to ask somebody, do you talk to them about it or do you ignore it with them like? Because you can't ignore with yourself because it's there"* **(C032, Mrs. Barry, care-partner, spouse)**

These comments made by Mrs Barry highlight the need for care-partners to be better advised as to how to broach issues concerning diagnosis at an interpersonal level. In this case Mrs Barry was obviously in a dilemma and clearly did not know what approach was correct for her husband.

5.3.3 Section summary

This section has examined how respondents made sense of their dementia and how they reacted to and coped with the various changes they were experiencing as a result. The data shows how for most of these men and women conscious and sub-conscious coping mechanisms were used. These included normalising the process and not discussing their illness with others. Such strategies helped respondents deal with the changes they experienced. Some seemed more aware than others that they were engaging in these behaviours. Many were aware that the changes they were experiencing were having a direct effect on those around them.

Respondents often attributed their cognitive and memory changes to recent events in their lives (family growing up, leaving work) or to changes in their everyday habits. This gave their memory and

cognitive changes a legitimate cause and a subsequent meaning. Interestingly few of these men and women attributed the cause to the illness, dementia. Findings show that both respondents with dementia and their care-partners adopted this approach.

Most respondents may not have had the words to say they had dementia or that they had a deteriorating illness, but they responded to symptoms and changes in ways which shows an awareness of the nature of dementia. They looked for explanations of why these changes were occurring and responded in what I perceive to be normal ways, e.g. frustration at not being able to find things, worry about getting lost and consequently being disinclined to go out again, accepting that things were not going to change, getting on with life, and worrying about those around them.

5.4 Coping Mechanisms

This section further examines the coping mechanisms used by respondents and how they managed the onset and progression of their dementia. Understandably dementia significantly affected respondent's day-to-day lives, but many found it very manageable:

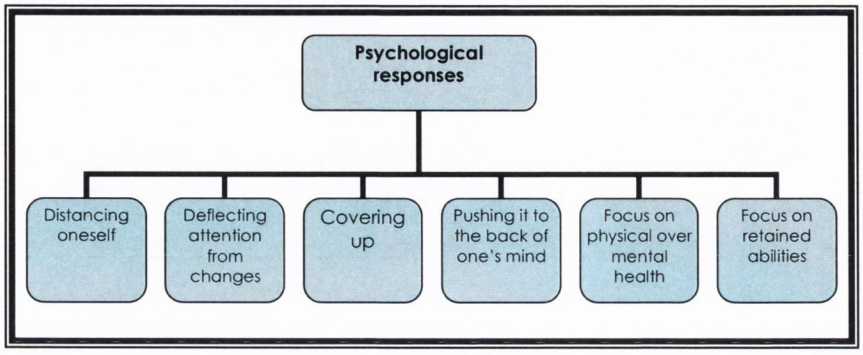
> *"On a day-to-day basis it's nothing"* **(018, Mrs. Buckley, female, 78 years, Alzheimer's disease, lives with spouse)**

This highlights how daily implications of the symptoms of dementia are not insurmountable. However, Mrs Buckley alludes to a reality outside of the day-to-day where possibly other people or other routines make the experience of having dementia 'something'.

5.4.1 Psychological responses as coping mechanisms

As respondents witnessed their changing and changed circumstances, many used important psychological responses to adapt. Data analysis revealed six different psychological responses adopted by these men and women. These responses are presented in Figure 5.2 below,

Figure 5.2: Psychological coping responses



(i) Distancing oneself

In some cases respondents distanced themselves from having a memory loss and cognitive changed by not identifying themselves as having the illness and by not being able to make connections between illnesses such as dementia that their first degree relatives may have had in the past and what they were now currently experiencing themselves:

> *"Respondent: Like, as you get older you do, sure my mother used to forget. She used to forget a lot, she had Alzheimer's...As you get older you start to forget things. I wouldn't say it (her own memory) was bad, bad you know what I mean. But I'd just go for the middle then. Interviewer: Are you worried at all because your mother had Alzheimer's disease? Respondent: No. Interviewer: Okay and you think it's just a normal part of getting older? Respondent: I, I think so"* **(038, Mrs Gannon, female, 62 years, Alzheimer's disease, lives with spouse and daughter)**

> *"It is like the illness is on the periphery of their subconscious. It is part of their discourse yet there is no acknowledgement of it as something they have"* (**researcher fieldnotes**).

This fieldnote was made in reference to the above quote by Mrs Gannon, whose mother had Alzheimer's disease. This concurs with Howorth and Saper's (2003: 120) finding that people living with

dementia, who often have good insight, rarely connect their disability/impairment with other family members' memory loss or dementia. During the interview I thought that Mrs Gannon was completely separating her experience from her mother's. However, another interpretation of this statement is that Mrs Gannon is associating age-related memory loss with Alzheimer's, viewing both as normal aspects of the ageing process.

(ii) Deflecting attention from disability

Another response mechanism used by participants, when memory loss, impairment or disability emerged in conversation, was to deflect attention from it. When Mrs Martin was asked about her memory, after confirming that she understood the question, she deflected attention from the issue:

> *"Interviewer: So can you tell me a little bit about your memory at the moment? Respondent: My memory? Interviewer: Yeah. Respondent: Well I have a wig. You know that do you? Interviewer: Yeah? Respondent: You wouldn't have known that only I told you but other people do say that too"* **(041, Mrs. Martin, female, 77 years, Alzheimer's disease, lives with spouse)**

Mrs Martin then talked about her wig for some time. It can be argued either that Mrs Martin had communication difficulties and understood the question in a different way to how it was asked, or perhaps she knew the question referred to this part of her anatomy (her head/brain) on which she now wore a wig and the association spurred another train of thought.

Mr Burns had quite severe and daily word-finding difficulties. On a number of occasions during my interview with him he would revert to the Irish language when he had difficulties searching for an English word:

> *"Interviewer: Do you prefer winter or summer? Respondent: Is cuma liom*[2] *(laughs)"* **(017, Mr Burns, 82**

[2] Is cuma liom means 'it doesn't matter'.

years, mixed Alzheimer's disease and vascular dementia, lives with spouse)

He was not a native Irish speaker, but he had been educated through Irish and his language showed a deep connection between language and coping. This interview with him made me think about how disadvantaged some people with dementia are when being cared for by staff who may be unfamiliar with the vernacular language[3].

(iii) Covering up

Others who were aware of their disability were adept at covering up and interestingly some were very aware of what they were doing as Mrs Griffith's testimony reveals:

> *"Interviewer: And have you spoken to anyone about it (her forgetting)? Respondent: No, no, this is something that I would hide (places her hands on her chest)... You see, I'm trying to, I read before about it, I read a lot about it and it said you cover up and let me introduce things themselves and then you might click back, you know. So I cover up"* **(024, Mrs. Griffin, female, 75 years, Alzheimer's disease, lives with spouse)**

In this case Mrs Griffin was speaking about letting others introduce topics of conversation first so her own memory would be refreshed. Mrs Griffin, during the first research interview, said she had a small amount of memory loss but she felt that it was normal ageing. At the second interview she spoke openly about being aware of having something more serious and knew that it was going to get worse. Interestingly and unlike Mrs Gannon, she directly related it back to her own mother's experience of dementia. Her response to this was to cover-up as a form of coping, not to think about it:

> *"Respondent: My father was on the ball Okay, till the day he died he was telling us you know, what to do (laughs). Ehh, no, my mother I'd say might have been but she was a great cover-upper. Interviewer:*

[3] The education system in Ireland requires all students to learn Irish from primary level through to the end of secondary level.

> *Was she? Respondent: Oh yes, she'd say 'yes I remember, yes, yes, yes'. I mean I'm going to be like her I think (laughs)"* **(024, Mrs. Griffin, female, 75 years, Alzheimer's disease, lives with spouse)**

Mrs Griffin recognised the difference between her father and mother's cognition. She recognised that her mother covered up a cognitive disability albeit unsuccessfully yet Mrs Griffin was still willing to use this as a strategy to cope herself.

Another possible reason for covering up was to avoid becoming a burden on other people. Some respondents expressed a desire to please people:

> *"I don't want to be giving anyone any trouble, you know"* **(032, Mr. Barry, male, 79 years, mixed Alzheimer's disease and vascular dementia, lives with spouse)**

(iv) Pushing it to the back of one's mind

Another common response to coming to terms with the symptoms was not addressing the problem, 'pushing it to the back of one's mind'; this could be to avoid feelings of anxiety, the desire to 'survive'. It was another way of coping:

> *"No, it is, I mean I, you know, you would survive. So no, they, they're sort of the little things that would be at the back of my head, like you know, I'd go and push them back further again (laughs)"* **(024, Mrs. Griffin, female, 75 years, Alzheimer's disease lives with spouse)**

Mrs Griffin said she knew her memory was going to worsen; she was anxious about it and the only way she could cope was to not face up to it or as she herself said "push it to the back of her mind and not think about it":

> *"I don't like it, I don't like it you know, that kind of way, I feel sometimes that emm, oh, it makes me anxious at times you know about myself and before I used to get anxious, forget it you know. But emm, I'm*

> *now more realising that this is what, this is the future you know, what am I going to do? But emm, other than that like emm, it's, it's something that's going to happen and I can't stop it, do you know? But other than, but kind of I don't emm, I don't dwell on it, I, I, I know it's there"* **(024, Mrs. Griffin, female, 75 years, Alzheimer's disease, lives with spouse)**

Even though Mrs Griffin said she did not dwell on it, there is a sense that the anxiety connected to her dementia cannot be addressed in the same way that other anxieties can be. Her words suggest a fear, a sense of powerlessness and a total lack of control.

(v) Focus on physical rather than mental health

Often respondents, whilst aware that they had problem, did not associate this with their health status and talked affirmatively about their good physical health. In other words, they did not correlate the changes witnessed in their memory and cognition with changes in general health status:

> *"I don't have a great health problem really, it's mostly the memory"* **(033, Fr. Hanrahan, male, 70, Alzheimer's disease, lives in religious community)**

> *"My health is, is very good. I have no problems with that. The only thing is we go out, if, anything we go to the doctor there would be something, very seldom. My health is perfect"* **(034, Mr. Doyle, male, 76 years, Alzheimer's disease, lives with spouse)**

I feel this relates to the stigma of cognitive or mental health problems. This finding concurs with the literature. Clare, Goater and Woods (2006: 765) in their study with 22 people living with dementia found that most respondents with dementia did not see themselves as having an illness, but acknowledged experiencing memory difficulties and forgetfulness.

Even when symptomatic awareness was high and respondents reported an awareness of the prognosis, greater emphasis was placed on physical ailments:

> *"Interviewer: So your actually physical ailment, the hip, is more significant than the memory? Respondent: This is, if I had that done I'd be still dancing. I don't know whether it's my hip or my back. I'm actually hopping on this foot when I'm walking"* **(018, Mrs. Buckley, female, 78 years, Alzheimer's disease, lives with spouse)**

Going dancing for Mrs Buckley and her husband was very important, it was the main part of their social life and she knew her husband missed it greatly.

When people enjoy good physical health, it is easier to cover up memory loss symptoms or pass them off as not being serious:

> *"Interviewer: And what factors are most important to your quality of life? Respondent: Well I suppose health, if that's still good I have no problems with it except what you have there (points to head). Interviewer: With the memory. Respondent: Yeah, that, that's not, at this stage it's not any problem but maybe a little bit of [a] nuisance"* **(023, Mr. Burke, male, 78 years, Alzheimer's disease, lives with spouse)**

Howorth and Saper (2003: 120) also found that people who acknowledge memory and cognitive change, when asked about it would often spontaneously mention other factors, particularly physical or sensory deficits, as being of greater significance. They argue that this is not denial but reflects a genuine order of priorities. Mrs Buckley's commentary is a good example of this, where she no longer went dancing due to her hip which was more important. It seems that, for her the hip problem posed a more significant obstacle to her independence that the difficulties caused by her dementia.

(vi) Focusing on retained abilities

Although respondents might have been aware of their memory disability, many focused on the things they were still able to do:

> *"I think I'm all right. I don't think I'm all right in regards remembering but I'm not, I know it's a very big thing, that's the main thing that is there but we're still having our ordinary life"* **(018, Mrs. Buckley, female, 70 years, Alzheimer's disease, lives with spouse)**

Her words remind us of an earlier quote where reference was made to managing on a day-to-day basis, Mrs Buckley knows the dementia is serious yet they have an normal life, which is more important to her that what will happen in the future. Stansell (2002) maintains that professionals narrow the opportunities of people living with dementia, by relating to them in terms of loss rather than by honing in on their retained abilities, thus hampering their continued contribution as members of society:

> *"Interviewer: And I think that was the day that you were given your diagnosis, that's when the doctor told you what was wrong I think. Respondent: Yeah that was, that was a bit scary, you know...Interviewer: How did you find it? Respondent: Well I think he talked more about driving and fuckin' everything, sorry, driving you know, get onto your thing and get, get to a solicitor and whatever that thing ... see I can't remember. Interviewer: Enduring power of attorney. Respondent: Yeah, he was telling me all these things, he wasn't telling me anything about my head"* **(030, Mr Murphy, male, 70 years, Alzheimer's disease, lives alone)**

The excerpt above suggests that Mr Murphy would have preferred to receive more in-depth information about his dementia at the time of diagnosis rather than being given advice about driving, legal and financial matters. He was frustrated and afraid because the doctor spoke about what he would lose not about what he would retain.

I think it is important to recognise the retained ability of respondents. Some continued to live 'ordinary' lives despite their diagnosis of dementia. Many managed very well on a day-to-day basis irregardless of having dementia and the manifestation of symptoms. At times it was a worry but they were coping well.

5.4.2 Short-term coping techniques

Data analysis revealed how the sample used different approaches to coping with their dementia. Short-term strategies included combating the symptomatic effects by:

(i) Having a little talk with oneself, calming oneself down:

> *"Emm, I sometimes am annoyed with myself that I've forgotten something and I, I, I say I have to better than this. And what I usually say to myself is get your act together Bernie (laughs)"* **(020, Mr. Watts, male, 82 years, Alzheimer's disease, lives with spouse)**

> *"Interviewer: Do you find your memory frustrating at times? Respondent: You would you know when I say to myself what's wrong with you get up, clue in"* **(035, Mrs. Doherty, female, 76 years, vascular dementia, lives alone)**

(ii) Plucking up courage:

> *"I'm not going to let it get me down"* **(010, Mrs. Curran, female, 74 years, Alzheimer's disease, lives with spouse)**

(iii) Taking a minute to collect oneself but *"it could be a long minute"*

> **(017, Mr. Burns, male, mixed Alzheimer's disease and vascular dementia, 82 years, lives with spouse)**

5.4.3 Other coping strategies

Other coping mechanisms were identified as humour, focusing on good days, implementing memory supporting techniques, drawing on past experiences of coping, informing oneself and talking about it. These themes are addressed in turn in the forthcoming section.

(i) Humour

eHumour was used by many respondents to help cope with situations and was seen as beneficial. These findings are in keeping with those reported in other studies with people living with dementia (Keady and Nolan, 1995b; Preston, Marshall and Bucks 2007; Snyder, 2001). Personally I think humour is good for both the heart and the mind, it is a way of creating and maintaining positive relations with other people. Findings show that it took some of the seriousness out of a dementia diagnosis and created positive feelings. Mrs Curran and Mr Murphy both clearly found laughing a good way of coping:

> *"You just have to laugh these things off you know...it gets rid of it"* **(010, Mrs. Curran, 74 years, Alzheimer's disease, lives with spouse)**

> *"I keep on laughing to myself about it you know, there's three things wrong with me, my heart, my lungs and my head. It's all you can do is laugh"* **(030, Mr. Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

Humour is a good mechanism to shield oneself from the judgement of others and subsequent stigma as a result. For example when they could not find a word, or stumbled over a sentence, it was often used as a diversion tactic:

> *"His em, what is it, there's a word for it .... (laughs) that's the word"* **(017, Mr Burns, male, mixed Alzheimer's disease and vascular dementia, lives with spouse)**

Even during the course of interviewing, several men and women displayed different types of humour, from self-deprecating to irony and wit. This type of humour was mostly used as an aid to cope with situations. In some cases humour was an integral part of personality, in others it was used to lighten the situation, placing a positive slant on their experiences:

> *"For two oldies we're not doing too badly"* **(020, Mr. Watts, male, 82 years, Alzheimer's disease, lives with spouse)**

> *"Interviewer: And when did you first notice that you were starting to forget things or that the memory was changing? Respondent: Now that would be a no-brainer because I can't remember (laughs)"* **(030, Mr. Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

In this quote Mr Murphy, displaying quick wit, draws attention to the slight absurdity of my question.

An analysis of the data also showed how humour was used in the caregiver/care receiver relationship, particularly when conversation focused on dementia or memory and cognition:

> *"Care-partner: Forgetting more things than usual, you know. I'd get a loan of twenty now of her and she'd forget about it (laughs). Respondent: You would not (all laugh)"* **(038, Mrs. And Mr. Gannon, Alzheimer's disease, 62 years, lives with spouse)**

Some respondents also referred to other family members and friends using humour in their reactions to them. It would appear that this was done to make the person living with dementia feel at ease and was a coping mechanism that helped both of them:

> *"Interviewer: And did you tell your friends and that when you got the diagnosis? Respondent: Ah yeah. Interviewer: Did you let them know? Respondent: Yeah, say oh it's your round now for the drinks, ah Jesus no, I think I did the first one (laugh)"* **(030, Mr. Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

The quote here also highlights the importance of the individual with dementia being made to feel accepted in social situations. When others accepted the diagnosis and treated the person as they had done in the past, this made it easier for the person:

> *"A lot of the family had moved on for a while, they moved back with us, a lot of them were stopping here at different places, it's very confusing for people that might have a poor memory (laughs)"* **(039, Mr. Callaghan, male, 82 years, mixed Alzheimer's disease and vascular dementia, lives with spouse)**

(ii) Every day is different

The data show that for the men and women in this sample every day was different. Several focused in their conversations with me on the good days, which probably helped them remain positive. Care-partners also reported a similar strategy:

> *"Interviewer: Do you think that she is coping with her memory problem Okay? Care-partner: Sometimes you know. It went today, maybe she would get annoyed and say I know that, I know that. So I say nothing then"* **(C018, Mr. Buckley, care-partner, spouse)**

> *"Oh yeah, but you see that's kind of the thing, each day, maybe not everyday is different but you can't be you know, it varies an awful lot"* **(004, Mrs Beattie, female, 67 years, Alzheimer's disease, lives alone)**

As Phinney (2002b: 330) states, awareness fluctuates "with the result that symptoms of dementia show up for people in different ways at different times":

> *"My mother [is] sometimes very argumentative. [She] doesn't like being, some days you know she just wants to be left alone you know, no fussing. Which is understandable you know"* **(C029, Ms Lynch, care-partner, daughter)**

There was also, at times, a conscious awareness of what one respondent referred to as hanging on, to consciously make the effort to stave off the progression of the illness by actively trying to remember things:

> *"That's why I am trying to hang on as long as I can, remembering you know"* **(018, Mrs. Buckley, female, 78 years, Alzheimer's disease, lives with spouse)**

(iii) Memory supporting techniques

Another coping mechanism, used by several respondents, involved employing memory supporting techniques. These ranged from keeping detailed notes (writing everything down), to the use of calendars:

> *"Sometimes I'd write on the calendar, I have a calendar on the desk and I jot down things"* **(033, Fr. Hanrahan, male, 70 years, Alzheimer's disease, lives in religious community)**

and training oneself to remember in particular ways such as associating activities with events:

> *"Respondent: I give myself little lessons, emm... Interviewer: Like what? Respondent: And emm, sort of put something down and remember that now and I know something is coming up I might go down and buy a pair of shoes for that, that kind of, I associate things like that, you know"* **(024, Mrs. Griffin, female, 75 years, Alzheimer's disease, lives with spouse)**

Curiously only one respondent, Mrs Beattie, had received formal training by an occupational therapist[4] on these techniques. I am unsure if this was cognitive behavioural therapy. However, it proved very successful for her. Another useful coping mechanism employed by Mrs Beatties was the use of visual prompts such as photographs, newspaper clippings and art work to facilitate her communication.

(iv) Informing oneself

Gathering information was another coping mechanism used by several of these men and women and their care partners. It was not unusual for them to gather information from newspapers, from other lay people and from professionals. Useful coping strategies could be

[4] This training was through a ten-week programme at a Day-hospital.

found in newspapers clippings about what could support memory, for example nutrition:

> *"I read they're good for your brain, about eggs. I read that, did you know that yourself?"* **(004, Mrs. Beattie, female, 67 years, Alzheimer's disease, lives alone)**

Information imparted by others was also considered important in the absence of formal information brochures or pamphlets being available through HSE services. It seemed that several of these people had very significant information needs, they craved information and latched on tightly to any help or advice they could acquire through the media or through their own personal networks. Care-partners' ability to inform themselves was sometimes dependent on who they knew:

> *"Ehh it was a neighbour of mine actually who works down in ------- clinic and she said it to me, she said you know she said your Mam is entitled to home help and ehh so she said it's about eight euro a week, for two days"* **(C029, Ms. Lynch, care-partner, daughter)**

> *"Care-partner: Well now, there's a woman across the road whose father has Alzheimer's and because she went away, she wanted to go away to see her daughter for the weekend, a man came in and stayed in the house and she didn't have to pay him. Interviewer: That's the respite care grant"* **(C029, Ms Lynch, care-partner, daughter)**

Mrs Griffin recalled other people she knew who had dementia and remembered how they coped. This showed a high level of awareness and skill in adapting to her situation:

> *"No I didn't read any literature, it 'twas someone I met, in the course of life that, that and I noticed that she was forgetting and ehh she would use leading questions and then everything came back to her. I*

do that" **(024, Mrs. Griffin, female, 75 years, Alzheimer's disease, lives with spouse)**

(vi) Talking about it

It has been suggested in other studies that talking with others (family, friends and professionals) about having dementia can be cathartic, where people can feel understood and more positive as a result (Preston, Marshall and Bucks 2007: 137). However, respondents in this study, for the most part, expressed no desire to talk to others about their experiences. In the case of Mrs Buckley who appeared to have a very close relationship with her husband, she felt talking to him about her dementia would upset him:

> *"I don't want to say it to Martin what's going to happen when I get worse and I don't want to ask him what he thinks about that, I just want to let it take it's course you know and that's what I would rather do and if he doesn't mention it. He doesn't shy away from it but we don't talk, we kind a just don't talk about it you know"* **(018, Mrs. Buckley, female, 78 years, Alzheimer's disease, lives with spouse)**

As in other countries, a primary focus of dementia care in Ireland has been on medical and pharmacological interventions. This was reflected in respondents' perceptions. Some did not see any benefit in discussing their dementia as it would not remedy the problem. Many respondents saw no value in psychological interventions, perhaps because they had no prior experience of them:

> *"Interviewer: And would you like to talk to somebody about it more? Respondent: Emm... What good would it do? I don't think it would do any good, unless somebody comes up with a big pill and says put that in your head and everything's all right and that's not going to happen"* **(030, Mr. Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

Another issue was that respondents had not been given the opportunity to talk to others about dementia and therefore they did not know whether it would be beneficial or not:

> *"Interviewer: Would you prefer to talk to people about it, would you like to talk to people about your memory? Respondent: Well I'm talking to you now, at the moment and I don't mind"* **(017, Mr. Burns, male, 82 years, mixed Alzheimer's disease and vascular dementia, lives with spouse)**

Another interpretation of this unwillingness to talk about their dementia could be that it required the person to disclose that they had the illness in the fist place and for many respondents this would mean that the recourse to covering-up would no longer be available to them. The issue of going public, breaking the silence and discussing the illness with those close to you, is very different from that of engaging the skills of a professionally trained person or counsellor. Also respondents, in the most part, were willing to talk to me about their experiences. I was a stranger to them. This is an issue which will be returned to in the final chapter of this thesis.

5.4.4 Section summary

The results presented in this section show how the coping mechanisms employed by the sample varied considerably. Day-to-day coping came easier than coping with the 'bigger picture' or the long term prognosis, possible because respondents were unsure what the future had to hold in some cases and in others they were aware of the deteriorative nature of dementia and chose not to think about it (pushing it to the back of their mind). In some cases respondents used psychological mechanisms to manage their dementia such as covering up or motivated denial. Most respondents spoke about immediate strategies of coping as symptoms presented e.g. taking a deep breath, relaxing. Long-term strategies were more complex.

Only one respondent had received memory support training from an Occupational Therapist. This worked quite well for her. Other

strategies included the use of humour to lighten situations, or focusing on positive aspects of their lives. Although talking about dementia might seem a good coping mechanism, for this group of respondents it appeared alien and was perceived as something that would exacerbate the problem. In the light of the respondents' reluctance to discuss dementia, findings from this part of the research do not concur with the argument, presented elsewhere in dementia literature, that talking about dementia is a good coping mechanism. These men and women's desire to refrain from talking about their dementia and the difficulties they were confronting may also have been influenced by wider social beliefs about dementia and the stigma often associated with having this type of illness (see Chapter Six, section 6.6 for a further discussion on this).

5.6 Chapter Summary

Findings from this study showed that levels of awareness of memory and cognitive disability varied across the sample. Hence, the thesis provides further evidence for the argument (see for instance Phinney, 2002b) that people living with dementia cannot be assumed to have no awareness. Most respondents reported awareness of numerous changes in their lives, including an awareness of symptoms despite the fact that they may have believed their memory *per se* was good or at least 'Okay'. A quarter of the sample had a high level of symptomatic awareness and insight into the nature of dementia and their likely future trajectory. However, virtually the entire sample reported some change and deterioration in their memory and cognitive ability, often describing experiences of changed ability in great detail. This offers further corroboration of Killick and Allan's (2002) view that awareness is not just about one's insight into having dementia. It also relates to awareness of other changes in the person's life e.g. changes to emotional responses, relationships with others.

Analysis of the raw data revealed that a number of respondents understood they lacked awareness and insight into what was

happening to them, i.e. they were aware of their lack of awareness. They accepted their diagnosis based on what they had been told. Some were aware that they would forget that they could forget. This awareness was often accompanied by altruistic worry about others, as many respondents were aware of the consequences of their symptoms for other people. They did not want to be a burden. This was accompanied by feelings of guilt, they did not want to infringe on other's lives.

The findings on the topic of awareness show that using quantitative approaches alone to investigate this complex phenomenon would have been insufficient as the use of Likert Scales failed to provide valid or meaningful accounts of the lived experience of dementia. Asking open-ended, non-threatening questions proved to be more useful. If we examine the use of Likert scale in research on intellectual disability (Hartley and MacLean, 2006), it has been shown that the use of pictorial representations and expanding on themes by using probing questions can further facilitate the unfolding of people's stories.

Using the Likert scales to measure self-reported memory problem showed that respondents tended to choose positive representations. As already stated, qualitative investigations showed that more complex processes were at play, with respondents describing experiences as a result of dementia which from an observer's point of view represented serious changes to their lives. An example of this is Mrs Curran, who reported having a good memory yet she described to me in great detail an incident in which she became disorientated on her way home one day and as a result she no longer had the confidence to go out alone. It could be interpreted that she did not go out alone because the experience made her too afraid and she did not want to repeat the experience. It also could be interpreted that she did not go out alone as she did not want to be recognised as someone who experienced disorientation.

Mrs Curran's description of her memory as good raises the question why did she (and other respondents) wish to present a positive front? Respondents may have wanted to present themselves in a way in which they thought would be more acceptable to me and the outside world. It could be interpreted that my role placed pressure on them to do so. Earlier in the thesis I stated that because I was connected to the hospital and to a well-known university people were more willing to become involved in the research project. But if I was seen as a representation of a formal institution, they could have also thought there were graver implications if they presented a 'non-socially acceptable' front. I tried to counteract this within the consent forms by ensuring that respondents knew that participation in this study would not have any implications to the other services they were receiving.

Brocki and Wearden (2006: 88) state that applying an IPA approach assumes that respondents seek to interpret their experiences in to some form that is understandable to them. This was true for respondents as they sought to apply meaning to the changes they were experiencing; while maintaining a sense of their own identity. Sabat's (2003) concept of Selfhood can shed light on respondents' wish to maintain this. Self 1 as outlined by Sabat (2003: 8) is the self of personal identity; where sense of self is expressed as a singular person, a unique individual, a person who is continuous and holds a single point of view in the world of time, space and object. Respondents applied a number of strategies to maintain this. For example, there was a search for understanding to the symptoms they were experiencing. Other strategies included covering up and normalising any changes which were a result of their dementia. Respondents often tried to normalise symptoms in the context of natural ageing, comparing themselves to others so they would not perceive themselves as different. Some also normalised symptoms by viewing it as a fault of their own, a consequence of laziness or inattention. This resulted in some respondents blaming themselves for the changes that adversely affected their lives and the lives of people close to them. It could also be argued that normalising and

covering up symptoms is a response to stigma. Some men and women in the study used expressions such as shame, feeling like a twit, and being embarrassed when describing aspects of their life relating to memory loss, which is suggestive of perceived stigma.

Findings show that respondents' reactions to symptoms were largely negative and emotional. However, this could be based on how I worded questions as many respondents were asked outright were they frustrated by changes they experienced as a result of memory loss. Other emotions than frustration which were expressed by respondents included anger, annoyance and sadness. However, in a number of cases where respondents spoke openly about having dementia they were coping well and adjusting to changes as a result. They spoke about being hopeful. Some were scared but others felt positive about the future. The widespread use of humour and implementing positive coping mechanisms creates a less negative picture of people's lived experience.

Psychological responses to dementia included that of distancing oneself from what was happening, deflecting attention from any changes or pushing it to the back of their minds and covering up any evidence of disability. In discussions about disability, some respondents tended to focus on physical illness and reported a greater concern with this compared to their expressed concern over their dementia, memory and cognitive impairment and disability. This may well be related to the fact that physical illness is not as stigmatising for the individual when compared with illnesses of the mind. While respondents tended to implement immediate coping mechanism as symptoms arose, long-term strategies such as addressing issues of future care (such as advance care directives) were not common.

In summary, findings from this chapter suggest that the people living with dementia in this study by and large coped very well with the early signs and symptoms of their illness and with the changes occurring in their lives because of dementia. There were, however,

negative emotional and psychological effects from the changes incurred as a result of having dementia. A common thread was that people cope well in day-to-day living but stepping outside of the day-to-day is more difficult for both the person and their care-partner. Drawing on aspects of the social disability model, it is possible that this is due to how others interact with them or the changed physical environment, and the felt stigma by how others reacted and interacted with them. The findings from this chapter very much reinforce Kitwood's views and perspective on dementia. He (1997) argued that there are many manifestations of dementia just as there are persons with dementia and the data here clearly bears testimony to this. Kitwood (1997) also argued that the environment often constituted a "malignant social psychology" which served to dehumanise and depersonalise the individual thereby accentuating their disability. Evidence of a malignant social psychology can be seen in some of the stories told by respondents, Mr Callaghan for example felt very demeaned struggling to complete a formal cognitive assessment, Mr Burns stumbling for words whilst his friends avoided helping him out. Kitwood also argued that despite having a dementia, people remain social creatures and continue to live in social worlds dominated by relationships, events and activities (Chapter Seven further discusses these issues). Their past experiences, roles and relationships, likes and dislikes can influence their daily behaviour.

CHAPTER SIX: FINDINGS AND DISCUSSION II: THE SOCIAL IMPLICATIONS OF LIVING WITH DEMENTIA

6.1 Introduction

This chapter looks at the ways in which respondents living with dementia interacted in their social worlds and in turn how their social world affected their experience of dementia. It addresses the question 'what are the social implications of having dementia?' A better understanding of the social implications of dementia is needed for devising psychosocial interventions that address people's needs. My own initial assumption in relation to this was that what people enjoy or find useful tends to be reflected in what they seek in everyday interactions and activities.

This chapter examines a number of key areas, including: (i) respondents' social networks, (ii) how they engage in a social world (work and leisure activities) and (iii) changes in participation (in social networks and in activities) after the onset of dementia, specifically looking at withdrawal. These areas emerged from data analysis and relate to the issue of belonging, hence this chapter adapts Slater's (1999: 97) conceptualisation of belonging, where for most people it develops "first within a domestic context, second within a community and educational setting and third through engagement in occupational and leisure activities". This definition of belonging helped to structure the chapter. Within the domestic context, elements of respondents' kinship and friendship networks are examined, along with an analysis of how these networks changed and adapted to the person's dementia. Within the community context respondents' relationships with their neighbours and the changing community around them are explored. Tied into each of these areas is a discussion of leisure i.e. social and recreational activities. Understanding these aspects of the lives of people living with dementia is particularly important as interpersonal relationships

and social networks have been shown to have positive effects on health, longevity and quality of life (Haynes, 2007).

There is extensive literature, both theoretical and empirical, on older people and their social inclusion/exclusion[xlvii]. However, an exhaustive examination of the complex literature on 'social inclusion' let alone an empirical investigation would have demanded a separate investigation and has not been undertaken in this thesis. Therefore, the focus here is on issues of social engagement and participation. Both of these incorporate the concept of belonging, where belonging is closely related to being connected socially (social connectedness[xlviii]) and therefore incorporates social networks. For people living with dementia, belonging to a kinship, friendship and greater community network supports them as citizens, as a central feature of citizenship is membership and participation in the community (Barton, 1993: 241). Therefore, this chapter draws on both social constructionism and the citizenship model/framework.

6.2 How did Interview Schedules Address the Social Implications of Dementia?

In the pilot interviews, the respondents were asked open-ended questions about their social lives and also prompted, where necessary, to talk about the activities they enjoyed or used to enjoy and about their desire to attend a Day Centre or become a member of any clubs or groups. Those who were members of clubs were asked to comment on their experiences. They were asked whether they would like to talk to other people about their experiences in, for instance, peer-support groups. In addition, questions around friendship and kinship networks evolved as interviews were being conducted. As a number of respondents in the pilot and initial

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[xlvii] Percival and Hanson (2005: 190) relate social exclusion to people with visual impairment but their definition is also relevant to people with dementia, where social exclusion is "the perception or experience of having needs that, if unmet, marginalize and further disadvantage people...both as service users and as citizens more generally"

[xlviii] Connectedness is the construction and successful maintenance of reciprocal interpersonal relationships (Ware et al, 2007: 469).

interviews raised these issues as important to them, questions relating to friendship and kinship networks were incorporated into subsequent interviews. I had not considered this issue as a major topic until I was out in the field. This is a good example of how my approach developed following the pilot interviews, in accordance with the principles of qualitative interviewing and IPA.

The respondents were also asked a series of structured questions about changes in their social lives before and after the onset of the illness using a Likert scale. I wanted to see whether using a quantitative measure would corroborate the qualitative data collected. Self-ratings on self-esteem/confidence were also sought.

Table 6.1 reports on respondents' rating of their social lives. Responses were based on a five-point Likert scale which included the responses very bad, bad, OK, good and very good.

Table 6.1: Social life rating at time of interview

Self-rating of Social life	Very bad	Bad	OK	Good	Very good	No answer
At time of interview	0	3	6	6	2	0
For a number of years ago	0	0	1	8	6	2

Respondents noted a change in their social life with findings showing an overall decline in self-ratings on social life compared with earlier years. Where 14 people had reported having a good or very good social life a number of years ago, only eight did at the time of interview. No-one reported a very bad or bad social life a number of years ago but three respondents did at the time they were interviewed. However, over half of respondents (N=8) felt that they had a good or very good social life at the time they were interviewed. Similarly to findings presented in Chapter Five on normalising the experience of dementia, the respondents generally expected a decline in their social life as they got older. Findings from the structured Likert scale suggest that respondents were aware of a

decline. Qualitative data supports this but respondents generally attributed this to ageing rather than to having dementia.

Reasons respondents' gave for a change in their social life were that they had 'slowed down' and their life was 'not as hectic' (Mrs Griffin). Mr Burke said it was because he was no longer working. Fr Hanrahan said that moving back to Ireland from living many years abroad had caused a decline in his social life. Mrs Lynch felt that ceasing activities that used to bring her into contact with her friends (she used to play cards but no longer did so) had led to a decline in her social life (see section 6.4 for further details on activities). Mrs Beattie, however, was the only respondent who openly discussed a decline in her social life as a result of having dementia and the medications she was taking for it:

> *"Interview: So are you socially very active? Do you go out with friends? Respondent: No, no. Interviewer: Used you before? Respondent: Yeah, I'd be the ringleader. Interviewer: What happened? Respondent: Ah no, I, I, I'd be too tired but I think it's all them tablets maybe. And sure what I was going asleep and the Doctor in ------- told me that"* **(004, Mrs. Beattie, female, 67 years, Alzheimer's disease, lives alone)**

6.3 Social Networks

The literature reviewed in Chapter Three on the lived experience of dementia illustrated the importance of social networks and the importance of these networks in supporting the person's sense of self. It highlighted the role of the family as the main social network for people living with dementia. This section looks specifically at kinship and friendship networks and how these networks had changed for the person since they developed dementia. A major theme which emerged from the data was that respondents had experienced a change in their roles within these networks due to both ageing and dementia processes.

6.3.1 Kinship Network

Data analysis showed that the family played a key role in facilitating the social engagement of people living with dementia or conversely impeding their social engagement. Immediate family, in this case, refers to the spouse (or partner), children, grandchildren, children-in-law, brothers and sisters and nieces and nephews.

6.3.1.1 Family as a social network

The literature suggests that the social networks of people living with dementia are family and household centric (Kirby et al, 2000; Wenger, 1994). People living with dementia have less contact with friends, neighbours and community groups. The findings of this thesis support this as respondents' families provided valuable support, interaction and social contact and they facilitated the person's continued participation by supporting and encouraging activity outside of the home (see section 6.4).

The majority of respondents in this study lived with their spouse (N=13). One person lived with several others in a religious community and two respondents co-resided with their adult children. Living with someone else can provide daily social contact and can counteract feelings of loneliness (Holmén, Ericsson and Winbald, 2000). In the four cases where respondents lived alone, there was still daily contact (either face-to-face or by telephone) with family members.

In the case of Mrs Martin, her daughter was one of her main social supports and companions. Although not visiting daily, her daughter took a keen interest in her mother's social activity, stimulating her through conversation and supporting her memory by asking her about her daily activities:

> *"Fidelma (daughter) would ring me every single day, she'd say 'Well Mam, how did you get on today? Did you have any visitors?' Oh I'll have to tell her about you (laughs)"* **(041, Mrs Martin, female, 77 years, Alzheimer's disease, lives with spouse)**

It was evident from the data that whilst respondents' inclusion in friendship networks and community activity was diminishing (see the section below on activity), their contact with family members was stable and in some cases was increasing. Grant and Wenger (1993: 89-90) state that in most cases kinship networks tend to be more stable than non-kin networks ('personal communities' are generally speaking more difficult to maintain). This was true for Mr Watts as he mentioned that most of his friends had died. When he was asked whether his family constituted his main social network, he responded:

> *"Oh yes, yes. And like the girls are good and my son, one of the sons in particular comes to me regularly. The others will call but emm, we'll go out and we'll have lunch or you know we do that. So I'm quite happy"* **(020, Mr Watts, male, 82 years, Alzheimer's disease, lives with spouse)**

As social networks diminished the prospect of becoming lonely became more of a reality:

> *"Ah things are getting I suppose lonely. You could be maybe living too long, that sounds a fallacy but you know, you have pals that are gone and you're still here. It's not too big a problem that but we're a fair number of family... Interviewer:* And are you lonely? Respondent: *"No, not really, well if I was I wouldn't admit it to you. But it's hard to be lonely in this atmosphere"* **(039, Mr Callaghan, male, 82 years, mixed Alzheimer's disease and vascular dementia, lives with spouse)**

This suggests that Mr Callaghan considers loneliness to mean being physically alone. In this context he cannot be lonely as there are many people around him. He says that if he did feel lonely he would not admit it to me. Is the focus here on admitting these feelings, that there is a shame or a stigma in this? Or is it that he would not disclose these feelings to me; an interpretation of this is that he is defensive about these feelings.

Two possible reasons may explain the importance of kinship networks for respondents. The first lay in their non-threatening nature and the second was because they were familiar. The dynamics of the family were understood and long-standing and consequently the person living with dementia did not have to worry about their position within it. For example, Mrs Lynch worried less about her actions in front of her children and felt she could be more open with them in expressing negative emotions:

> *"At least, at least I can fight with my family (laughs)"*
> **(029, Mrs Lynch, female, 87 years, Alzheimer's disease, lives alone)**

Another interpretation of this statement is that Mrs Lynch has negative relationships with her family. However, Mrs Lynch's statement also indicates that she did not have to conceal annoyances or anger from her family members.

In one case where the respondent had lived abroad for many years, he found it difficult to renew contact with his extended family and his social network when he returned to Ireland. Over the years he had lost touch with most members of his family and was therefore in later life not receiving the benefits of having a close family to support him:

> *"Respondent: You see when I, when I was young, when I was a seminarian and all that, even in the first years when I used come back from Africa and so on I used to go round and visit ehh my cousins and family and friends I had you know, but gradually it goes out because after a while you don't know the families, you know. You just go visit once and you miss it the next time for example something like that, well you feel then, you kind of, you loose out you know. So I feel I've lost a lot of, those old friendships with families and things like that you know. And even some of my cousins they attack me a bit (laughs). Interviewer: Do they? Respondent: Yeah, I don't go much now really. Interviewer: What would they attack you about? Respondent: They just, 'when [are] you coming' and*

> *'why didn't you come' (laugh). A little bit, I'm exaggerating that a small bit. But I don't really go"* **(033, Fr Hanrahan, male, 70 years, Alzheimer's disease, lives in a religious community)**

Fr Hanrahan uses strong language to indicate the pressure he feels from his extended family. The beginning of this quote presents a man regretting the loss of an extended network but by the end it appears that he does not necessarily want to renew these contacts.

In other cases social contact with families revolved around inter-generational activities. This respondent and his care-partner show here how their family provided a valuable source of social contact and activity:

> *"My family are all the same things, they're all musicians you see and we go with them to things and where their children are playing or something we go to that, you know"* **(C039, Mrs Callaghan, female care-partner, spouse)**

6.3.1.2 Family strongly linked to quality of life

The World Health Organisation (1997: 1) defines quality of life as "a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment[xlix]". When respondents were asked what factors were most important to their quality of life, eight men and women independently (without any guidance or prompting) mentioned their families.

Families who played a key role in supporting respondents provided a sense of familiarity and comfort which promoted a sense of safety and which in turn helped to bring about a positive psychological state:

[xlix] WHO full definition of quality of life, "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationship and their relationship to salient features of their environment" (WHO, 1997: 1).

> *"As long as I have Fran [her daughter] and the boys [her sons] that's it...I think it's (quality of life) my family"* **(029, Mrs Lynch, female, 87 years, Alzheimer's disease, lives alone)**

Having a companion and a close relationship in older age was an important aspect of quality of life and the close spousal relationship was a common theme:

> *"Interviewer: What factors are most important to your quality of life at the moment? Respondent: Well I'm lucky in as much as, the boys and the girls and my wife, this is my second wife now, my first wife died. And em, I was very lucky to meet somebody like her"* **(020, Mr Watts, male, 82 years, Alzheimer's disease, lives with spouse)**

Mrs Griffin spoke indirectly about her dependency on her husband and about her fears of being lonely if her husband died. She knew her family would be there for her if this happened but the relationship she had with her husband was different:

> *"I would [be lonely]. But then kind of I know the family are around and they, it wouldn't be the same you know. Because they have their families and you can't intrude you know. No, I think I would miss my husband if anything happened to him"* **(024, Mrs Griffin, female, 75 years, Alzheimer's disease, lives with spouse)**

By using the word 'intrude' Mrs Griffin suggests that she is not part of her children's families in the same way herself and her husband are a unit.

Holmén, Ericsson and Winbald (2000) identify two types of loneliness, emotional and social. Ainsworth (1985) as cited in Holmén, Ericsson and Winbald (2000: 178) state that emotional loneliness is the absence of confiding and intimate attachment, loneliness is experienced due to separation, anxiety, restlessness and emptiness.

Social loneliness refers to a lack of a meaningful friendship; often the most meaningful friendship for someone is the relationship they have with their spouse:

> *"We have a very good family around me and particularly her nibs [his wife]"* **(032, Mr Barry, male, 70 years, mixed Alzheimer's disease and vascular dementia, lives with spouse)**

Mr Callaghan's wife noticed that as his dementia progressed he was becoming more and more bound to his home. As a result of this, their family was becoming a more important facet to the maintenance of her husband's quality of life:

> *"Well the quality has gone down a wee bit naturally, well what is quality now? Maybe not getting out as much or that but we still go to the concert hall and the quality is all right because my family are all the same things, they're all musicians you see and we go with them to things.... Quality of life is not bad for our age at all, we're not running around as much maybe we're running too much I think, we're running around too much"* **(C039, Mrs Callaghan, female, care-partner, spouse)**

Mrs Callaghan expected that with advancing older age her husband's (and her own) quality of life would diminish, as their ability to do things decreased and they physically were not as able as before to do things. Mrs Callaghan's social activity was also inextricably linked to her husband's (who had Alzheimer's disease) and when he became less able to do things, it affected her willingness to engage in social activities without him.

Another woman with dementia, Mrs Buckley also noted that her changed abilities affected her husband:

> *"Well there's no use saying getting rid of this, Alzheimer's, but to be able to go out and dance would be a great factor because it would be bringing Martin out, he is, I know he is and he never*

> *says anything. I know he's missing it because we have friends there, it's great, it was a good, big part of our lives that. And that's a bad thing there"* **(018, Mrs Buckley, female, 79 years, person living with dementia, lives with spouse)**

Mrs Buckley acknowledges that having Alzheimer's disease prevents both herself and her husband from doing things; not just the physical activity but also the social contact and engagement. They were a very close couple, but they did not talk about her illness or the effect it had on either of them.

6.3.1.3 Increased supportive role of family (part of care/support network)

Data analysis showed that when symptoms of dementia became more pronounced, care-partners and family members often took on a greater supportive role. In many cases people living with dementia became reliant on these supports, this was generally a response to try and facilitate the illness:

> *"If it was something important, I would never forget something important because he (spouse) would be there and, I mean, he remembers everything"* **(024, Mrs Griffin, female, 75 years, Alzheimer's disease, lives with spouse)**

This type of family support promoted overall well-being.

It was noted that increased reliance was often a result of a lack of confidence:

> *"Care-partner: She used to go into town every Friday to meet the sisters and ehh now won't go. I mean the odd Friday if I have the time I'll, she won't go in without me. Interviewer: Why is that? Why? Respondent: I don't know. I don't like going on my own. I like to have somebody with me. Interviewer: Why is that? Respondent: I don't know. Interviewer: Are you less confident? Respondent: Less confident*

> *yeah"* **(029, Mrs Lynch, female, 87 years, Alzheimer's disease, lives alone)**

Another respondent, Mrs Curran referred to how she got lost coming home one night:

> *"I never went anywhere on my own after that"* **(010, Mrs. Curran, female, 74 years, Alzheimer's disease, lives with spouse)**

As a result of this incident Mrs Curran decided she would no-longer go out by herself, the experience had been too traumatic for her. From that point on she was always accompanied out by her husband or another family member. Such experiences and particularly loss in confidence can have long-term implications by discouraging mobility and limiting independence.

Siblings were also mentioned as an integral part of social networks, gradually taking a supportive/caring role:

> *"Interviewer: And her relationship with family and friends hasn't changed? Care-partner: No it hasn't. I think her family now are, since the last mishap she had, when she got lost, I think her family are aware that she has a problem with that thing and if she doesn't get a lift home for instance, if she goes missing they call me and I go down to collect her. They don't just put her on a bus like they used to. Interviewer: Have you all talked about it? Care-partner: We never really talked about it. They kind of just know"* **(C010, Mr Curran, male care-partner, spouse)**

As in the case of Mrs Buckley, there is knowledge that other people know and are affected by respondent's illness but they do not talk about it openly. In Mrs Curran's case her family became aware when there was a serious incident, where she became disoriented coming home one day. Since then her sisters were aware of her illness and their understanding and assistance had a positive influence on her and on her husband. They picked up the presence of her cognitive disability quickly and it suited the respondent and her care-partner

not to talk about it as Mr Curran particularly did not want to disclose it to others as he felt that this would upset his wife. There is fear that the person living with dementia (in Mrs Curran's case) or the care-partner (in Mrs Buckley's case) would get upset if they spoke about the dementia.

In the case of Mrs Doherty who was beginning to rely on her daughters more, the following quote suggests that there was a power imbalance in their relationship:

> *"Interviewer: Will you go on holidays with the family or by yourself? Respondent: Oh no, go with the family, go with one of the girls, Marion and I usually go. Interviewer: And I hope you have a lovely time now with your couple of weeks holiday. Respondent: Ah I will. As long as we don't fall out (laughs). Interviewer: Do you fall out often? Respondent: No we don't (laughs). I know what side my bread is buttered on"* **(035, Mrs Doherty, female, 76 years, vascular dementia, lives alone)**

Other changes in familial relationships, identified through data analysis, included increased contact with children:

> *"Respondent: Well I have Trish [daughter] here and she's great, they're my children are, are, even Anna who's working in, in, in Munster like, she has a big government job and she phones every night. And she calls every, very seldom, often even. And emm Jim, tonight now he calls, when he can with his work, but he comes fairly often. Interviewer: And do you get lonely in the house here by yourself? Respondent: Well I'm, I'm seldom by myself there's always somebody here"* **(036, Mr Moore, male, 93 years, mixed Alzheimer's disease and vascular dementia, lives alone)**

Like Mr Callaghan earlier, Mr Moore makes an association between loneliness and being physically alone.

> *"Care-partner: Then my brother is in, usually around what five thirty? Respondent: Yeah. Interviewer: And he comes in everyday for his dinner? Care-partner: Just to have something to eat, make sure she eats something"* **(C029, Ms Lynch, female care-partner, daughter)**

Family contact and regular visits were often for practical reasons such as a food preparation and housework and in some cases care-partners would have preferred more quality time with their loved one:

> *"I think if somebody was coming in here say even once a week and hoovering down the place, kind of cleaning the toilets it would be an awful great help you know, at least I wouldn't be kind of rushing in, running around doing a few things, I could actually sit down for an hour or so and have a cup of tea and a chat"* **(C029, Ms Lynch, daughter care-partner)**

In this case, Ms Lynch felt that the physical and practical care she provided needed to be reduced so she could spend quality social time with her mother.

In other cases dependence on family members generated feelings of guilt:

> *"Thank God they do come you know. Not that I need them to come because they have their own families now you know, they have their jobs and that, they do it and that's it. Ah no I don't mind, once they're keeping well and the phone is always there to them if they want to... they come in and out and that they know, but maybe they oughtn't"* **(041, Mrs Martin, female, 77 years, Alzheimer's disease, lives with spouse)**

Mrs Martin began this statement by expressing appreciation for the company and support her children provided, but she did not want them to prioritise her, especially as they had children of their own.

Whilst some families facilitated and supported the person's retained abilities, in other cases family or care-partner interventions had a negative impact on their relatives' independence. The biggest problem arose when care-partners began to take control and the person living with dementia became powerless:

> *"Well I suppose like in the crowd you know when you're in families sometimes you feel like even, I don't know, but there was some little thing anyway. I felt like they were organising things, putting me in my corner as it were"* **(033, Fr Hanrahan, male, 70 years, Alzheimer's disease, lives in a religious community)**

In other cases the person's confidence was affected by the fear of making a mistake. They felt a potential for embarrassment and sometimes looked for someone else to do different tasks for them, rather than attempt to carry them out themselves:

> *"He's [a] terrible independent character, he's more dependent now all the time you know. He'll say I have to pull myself up sometimes because he'll say do something or get something when he's well able to do it himself and I have to say no you get it"* **(C017, Mrs Burns, female care-partner, spouse)**

Mrs Burn illustrates the importance of care-partners' and family members' level of awareness of the abilities people can maintain and willingness to promote them. Another example is Mrs Watts who encouraged her husband to remain active around the house:

> *"Now in the kitchen I've noticed he'll forget where to put things, you know. You know the presses, I'd say to him get down that glass and he'll go to the wrong press. He won't remember where the press is. And I'll say no not there. And I make him do, no I don't make him do the washing up we have a dishwasher but I make him kind of tidy up and that. After I'll get the dinner ready and I'll say you put the dishes in the dishwasher"* **(C020, Mrs Watts, female care-partner, spouse)**

However, Mr Watts preferred if he did not go out alone, for fear he would be *"skipping out in front of a car"* **(fieldnotes, 020, Mr Watts, T0, 09/03/06)**. This meant that Mr Watts was relatively bound to his house and dependent on other people to accompany him when he wanted to go out. In an attempt to protect her husband, Mrs Watts reduced her husband's contact with the social world outside of their home.

Care-partners often had other competing responsibilities and roles, especially in the case of adult children. For instance, Mr Moore's daughter was still in paid employment:

> *"Interviewer: Are you in paid employment at the moment? Care-partner: Part-time. Interviewer: Part-time. And has your paid employment changed at all because of the situation with your Dad? Care-partner: Emm, I have refused to increase it, so that's, I mean I have only been doing two hours a week this year and I didn't try for anymore when the hours dropped because there was no way I could manage it anyway"* **(C036, Ms Moore, female care-partner, daughter)**

Mrs Lynch's daughter felt that she was effectively running two homes:

> *"So I'm sort of running down making Mam's dinner, making sure everything is OK you know, tidy, get her up"* **(C029, Ms Lynch, female care-partner, daughter)**

These two quotes suggest that there is a need for further formal support to assist both the person who has dementia and those family members who support them. In both these cases care-partners were daughters who did not live with their parent.

6.3.1.4 Giving and maintaining space

While in many cases the family became the respondents' main social network, some respondents wanted to remain independent from them, respecting each other's space:

> *"Interviewer: Would you see your other children that live in Dublin often? Respondent: Oh yeah, well I*

mean... we all like our own space but we do see one another maybe once in the week you know and then we might see one another one after another for a few days and I'd say ahh (laughs)" **(024, Mrs Griffin, female, 75 years, Alzheimer's disease, lives with spouse)**

"As far as the family is concerned we have sort of said not to be worrying about it you know. That I'd call on them if needs [be]" **(C041, Mr Martin, male spouse care-partner)**

Some respondents recognised their kinship relationships as reciprocal. Reciprocity supported their role within the family. Familial roles, though changeable over time, can support the person's sense of identity and reciprocal relationships gave value and meaning to the person's role as someone of worth, particularly as other roles and abilities start to change:

"Respondent: Ah no, we're all together like, you know, I mean if anybody needs us, we're there for them" **(024, Mrs Griffin, female, 75 years, Alzheimer's disease, lives with spouse)**

6.3.1.5 Changing role in the family

The above section on maintaining space is linked to respondents' changing roles within their families. In many cases this was due to the ageing process and not necessarily due to respondents' dementia. Changing family roles mostly affected female respondents, as they had been the primary caretakers of children:

"You see, everyone, they're all grown up now (children), they are all going their own way" **(038, Mrs Gannon, female, 62 years, Alzheimer's disease, lives with spouse and daughter)**

This is interesting also because this changing role was not due to Mrs Gannon having dementia but due to natural life-cycle changes.

"The girls are always in and out but it is, when you raise seven children and then you're left on your own

it gets a bit, it's a big shock to get... (trails off)" **(035, Mrs Doherty, female, 76 years, vascular dementia, lives alone)**

Changing roles can demand a great adjustment as a person's sense of their own identity is often connected to their past roles.

In another case Mr Burke's role in the home was as the primary bread-winner and he had always been responsible for looking after the household finances. However, with the development of his dementia this role was eroded and this changed his relationship with his wife:

*"Interviewer: Who looks after the financial things in the house, like bill paying? Care-partner: I do all that. Interviewer: And have you always done all that? Care-partner: Not always, but ehh that's another thing I haven't mentioned his concept of money. I don't think he realises the difference between 100 euro, 1000 euro or 10000 euro, or 100000 euro, there's a lack of concept about money. So I took over al the bill paying, oh a few years back. I don't know why I did it because he used to do things like paying Mastercard, things like that in the ATM machine. But at the moment now I have actually taken his cards, the ATM card and Mastercard because I'd be a bit afraid he'd loose his wallet and then that has to be you know, replaced"***(C023, Mrs Burke, female care-partner, spouse)**

This quote also provides us some with insight into the extent of Mr Burke's dementia; he had displayed symptoms of the illness 'a few years back'. His wife adjusted and continued on without a diagnosis being given at that time. Diagnosis will be examined in greater detail in chapter seven.

6.3.1.6 Section summary

A person's relationship with his/her family can be vital for the maintenance of a positive and active social network which facilitates

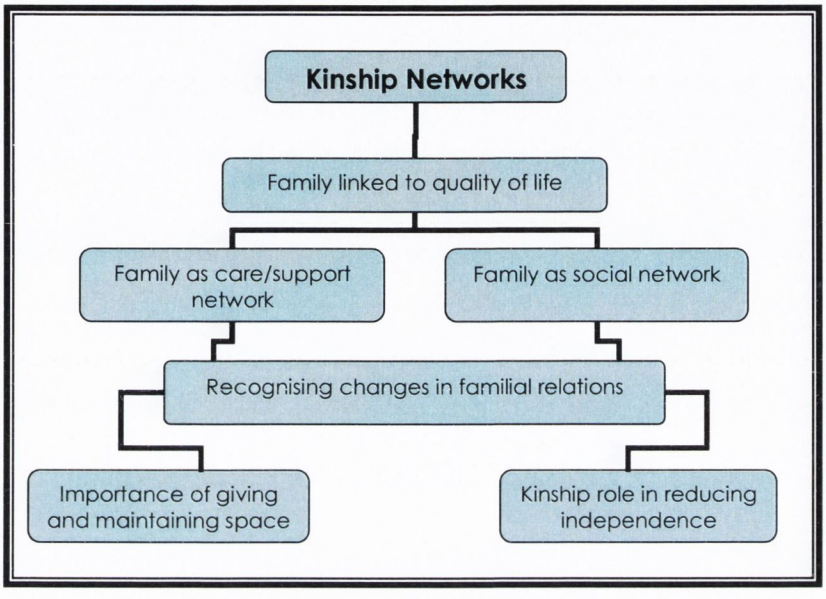
participation. In the vast majority of cases respondents had good relationships with their families and were in contact with them regularly. However, good relations and closeness did not always equate with openness or social connectedness. Often respondents and care-partners did not talk about the dementia and the effect it had on them. Reasons given for this were that they did not want to cause upset. A consequence of this can be feelings of guilt and possible misunderstanding.

A fundamental component of kinship networks is that they provide stability, particularly when friendship networks start to diminish. Fr Hanrahan had a complex relationship with his siblings but he was still in contact with them. In all other cases respondents had daily contact with their spouse, siblings and/or their children. Data showed that family support was very important for respondents in this study. Families were also strongly linked to quality of life. Under this topic respondents referred to kinship networks and spoke about their relationship with their children and their siblings. Not surprisingly, spousal relationships were mentioned as most important to respondents. As a result of reduced ability some respondents were beginning to depend more on their families and care-partners. This increased dependence could also be construed as a coping mechanism to maintain safety and avoid harm.

In some cases a paternalistic relationship emerged as a consequence of respondents' having dementia. This was often based on a wish to protect the other person. Care-partners, working in what they perceived were the best interests of the person, could have a negative effect on the recipient. At times, care-partners took on this paternalistic role as a result of being burdened by other duties. Where care-partners were children they often had other work and familial obligations. It can be difficult, in an unsupportive environment, for families to facilitate, encourage and support the person's independence.

Figure 6.1 summarises the main themes relating to kinship networks, emerging from the findings of this research.

Figure 6.1: Components of kinship networks



An important finding in this section is the salience of respondents' role within the family. It was found that reciprocity can help to maintain the person's sense of identity. How family members engaged and interacted with the person was very important. A desire to have space and in this way maintain the status quo within the family structure was also stated. The model shows how there is a duality between kinship networks in caring/supporting and promoting sociability, both of which are inextricably linked to a person's quality of life. There is a distinct and important difference between family as a social network and family as a care/support network. The model suggests that this balance is enhanced by maintaining space within the family but countered by the family at times reducing independence. A possible reason why there was often no open communication between care-partners, respondents and other family member about the person's dementia was that this would have challenged existing roles and caused distress.

6.3.2 Friendship networks

In this section, findings from the research on friendship networks are presented. Findings are discussed using two broad headings; the first looks at respondents' networks that consisted of groups of peers, with similar interests and tastes. The second focuses on the social supports that were provided by neighbours. These emerged as two distinct thematic areas from data analysis. Relationships with neighbours, in most cases, were not as close as other friendship networks but they were nonetheless a valuable outlet for respondents in this study.

In the course of the in-depth interviews respondents spontaneously referred to their friends and their friendship circles. Data analysis revealed how friendship networks were different to family networks and met other needs. They helped sustain feelings of value and self-esteem. Indeed, friendship networks can be more successful than relationships with children in achieving this (Slater, 1999: 99). It is therefore important that they are encouraged and maintained as the person's dementia progresses.

6.3.2.1 Peer groups

Most respondents belonged to some form of a friendship network. In many cases it depended on their current and previous activity, such as religious interests and involved contact with like-minded people:

> *"Respondent: We meet up in the church every morning, I go to ten o'clock mass... Interviewer: And would you have friends, many friends, a group of friends or..? Respondent: I have yeah, I meet them at mass every morning, we exchange the gossip (laughs)."* **(035, Mrs Doherty, female, 76 years, vascular dementia, lives alone)**

By meeting her friends at mass each day Mrs Doherty was also involved in the local community.

Other respondents had old school friends or work colleagues whom they met with regularly. In most cases these friendships had existed over a long period of time. They revolved around routines, meeting

on the same day and in the same place. These two elements (same day, same place) fostered the maintenance of friendship networks and raised less of a challenge for the friendship to continue as the dementia progressed:

> *"But I suppose I still pal with my same friends that I worked with. I still go out with them. I always go out on a Saturday night now"* **(038, Mrs Gannon, female, 62 years, Alzheimer's disease, lives with spouse)**

> *"Yeah, yeah we still have friends from when we were married first you know. We lived with the navy and then some of them are retired now in Dublin, we meet. We don't kind of live in one another's pockets but they play bridge too, you know. So it's kind of an ongoing relationship you know"* **(024, Mrs Griffin, female, 75 years, Alzheimer's disease, lives with spouse)**

One respondent, Mr Murphy, said that since his diagnosis his friends continued to treat him the same way they always had. As a result, his dementia did not interrupt any contact he had with his friends and he was able to maintain his identity within this network. His friends knew his diagnosis and did not change the way they interacted with him; as a result of this he felt he still belonged:

> *"Yeah well, I have good friends and all that sort of thing and ...they don't say they don't say anything about, you know, 'God don't mind him he doesn't know what he's saying' or anything like that, they're not like that, you know. They don't, what's the word...ostracise ya, you know. 'If you're in a crowd you're not stuck with him', they're not like that"* **(030, Mr Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

This adheres to Slater's (1999) viewpoint that relationships, including friendships, nourish our sense of place, our sense of personhood and our self-esteem, especially when the diagnosis is known and

accepted. These quotes also show how some respondents were very much engaged in social and peer groups.

For most respondents telling others about their dementia had a positive effect on their relationships and adheres to what Hutchinson, Leger-Krall and Skodal Wilson (1997) call 'open awareness' within the Awareness Context theory, where the diagnosis is known and openly discussed. It is argued that this context has the most positive outcomes for people living with dementia. In the minority of cases where people outside of the immediate family had been told, they tended to be key members of the respondents' social networks, close friends or neighbours. In these cases friends who were told began to adapt and change, helping to facilitate the continued participation of the person living with dementia in the friendship network. In their understanding, friends supported the person, while also supporting their care-partner. Other people who knew their diagnosis seemed to take greater care with the person living with dementia:

> *"Care-partner: Oh yeah, Riona two doors away and the lady next door, they're very good. Riona two doors away, I love her coming in because her and Christie used to be in the painting class together and her and they seemed to hit off one another, there's always a bit of a laugh when Riona comes in here. She's great with Christie and they seem to get on great and I love seeing Riona coming in and I'd say to her come in, in a few days time. Interviewer: And they all know that (respondent has dementia)... Care-partner: Oh they all know, yeah"* **(C018, Mr Buckley, male care-partner, spouse)**

Often respondents had to implement coping mechanisms and adapt to changed abilities to sustain friendships, for example using the telephone to maintain networks rather than meeting people in-person:

> *"Interviewer: And do you have close friends? Respondent: Ah yeah, ah gosh yeah. Interviewer: And would you see them often? Respondent: Ah*

> *well, well, no I wouldn't see them like that often. But I ring them and that you know, ah yeah"* (**004, Mrs Beattie, female, 67 years, Alzheimer's disease, lives alone)**

Elements of respondents' friendship networks promoted belonging (to the group and larger community) and routines around one's network fostered relationships (e.g. meeting at the same time and place each day) and supported a sense of identity, provided social contact and supported the person throughout their life-course. Dementia disrupts the person's cognition but friendships that were maintained throughout the life-course provided stability and promoted the idea of continuity in the respondent's life.

6.3.2.2 Stimulation

The importance of stimulation was reported by many care-partners, who identified friends as providing positive stimulation for the person living with dementia,

> *"If any of our friends come in here they'd say to me there's nothing wrong with her. They can't see anything wrong because she lights up when they come in. She's back to her old self you know that way"* **(C018, Mr Buckley, male care-partner, spouse)**

Reflecting on this quote three possible reasons why other people did not notice respondent's changed ability emerged, these were: (i) respondents covered up their disability, in company, (ii) social contact and interaction brought out the best in the person, (iii) the nature of dementia is such that a person can have periods where he or she remains very lucid. Familiarity and being at ease were reported as factors in the 'brightening-up' of the person living with dementia, being at their best when interacting with people they felt most comfortable with:

> *"I feel that the social outing is very important for her and I feel like, I don't know if she knows it herself but when we go to the pub and she meets her sisters and a group of friends, emmm, she just brightens up.*

Like it's amazing the effects of the company and chat and stuff like that, a different person, you know"

(C010, Mr Curran, male spouse care-partner)

Another care-partner noted the positive effect on her husband when her brother spent the day with him:

"My brother was great with him yesterday they just, I never saw him (respondent) so well for a long time. That was stimulation I think...they have the same interests you see, eh, music and trains you know"

(C039, Mrs Callaghan, female spouse care-partner)

Engaging with people who had similar interests made interaction more natural and non-threatening. It is important that the continued interests of the person living with dementia are identified and this is stimulated through engagement in conversation or activity around these interests, thereby promoting connectedness and placing value on the person's social currency[1].

Another form of stimulation was identified in the data as keeping active and busy,

"It keeps my mind active" **(018, Mrs Buckley, female, 79 years, Alzheimer's disease, lives with spouse)**

Activities are examined in greater detail in section 6.4.

6.3.2.3 Changing friendship networks

In many cases respondents noted that their friendship networks were getting smaller or eroding. Many reasons were put forward for diminishing friendship networks. These included the death of friends:

"An awful lot of them (friends) have passed on you know" **(C029, Ms Lynch female care-partner, daughter)**

Retirement:

"Well you see since I left the guards (former employment) I've left a lot of friends behind" **(034, Mr Doyle, male, 76 years, person living with dementia, Alzheimer's disease, lives with spouse)**

[1] Ware et al (2007: 471) argue that social currency is needed to successfully achieve real social connectedness. It is the personal attributes that spark the interests of others in connecting with them.

Some respondents were experiencing increased difficulty in social situations due to symptoms of dementia (this will be furthered examined in section 6.5):

> *"Interviewer: Did you have a good group of friends through the bridge? Respondent: Oh yes I had, I had. But then the memory gets so that it wasn't, you couldn't remember what cards you had in you hand (laughs). Interviewer: That hampered it a bit. Respondent: Exactly"* **(029, Mrs Lynch, female, 87 years, Alzheimer's disease, lives alone)**

It is important to note that not all changes in friendship networks were negative. In some cases respondents were making new friends. New social circles were mentioned, as a result of taking up new activities such as attending the day centre,

> *"I do [like] (the club) because then you're meeting more people, you see as you grow older your friends go further away"* **(041, Mrs Martin, female, 77 years, Alzheimer's disease, lives with spouse)**

It is thus evident that at least some, and possibly most, people do have the potential, ability and willingness to forge new friendships after the onset of dementia; a more detailed study of these relationships developed once dementia has been diagnosed would make for a fascinating new foray in dementia research.

6.3.2.4 Neighbours

Most respondents had lived many years in the same locality, raising their children and working in the area. Having good neighbours maintained respondents' connectedness to their area: "The feeling of being part of a whole" (Ware et al, 2007: 4717). These relationships may not have been as close or intense as those within their kinship and friendship networks, but they provided social contact and helped to maintain respondents' sense of belonging. Data suggested that in most cases these relationships with neighbours were on a relatively superficial level:

> *"Respondent: When I'm talking to somebody, one of the neighbours or anything like that, they're short, you don't talk for very long with them, I don't know why, I think it's just that they spend most of their time inside in their houses. I'd be walking along and the extraordinary thing is of all the houses that are here I only still would meet maybe two, I'd have walked up as far as the square and coming back again. Because people now eh, they seem to spend a lot of time in their houses. Interviewer: They're not as friendly, maybe are they? Respondent: Well I don't know what it is, I think it's I suppose yes, getting on in years like myself, you know. Well I stand up and talk, I don't know whether it helps or not"* **(023, Mr Burke, male, 78 years, Alzheimer's disease, lives with spouse)**

This also illustrates the differences between friendship networks and relationships with neighbours.

> *"Ah I would, now these (points to next door) are comparatively new but very nice, they don't infringe on you, like you know"* **(041, Mrs Martin, female, 77 years, Alzheimer's disease, lives with spouse)**

> *"Interviewer: And would you have a good social life? Respondent: Not really no, because her eh, the neighbours I'd talk to them all and I'd know a few of them all right but it would have to be a good day you know. There is a few people all right that I would call into their house, I would go into them if I had a problem"* **(023, Mr Burke, male, 78 years, Alzheimer's disease, lives alone)**

Some respondents were beginning to spend more time at home, because of their dementia (see section 6.5 below on withdrawal) therefore having neighbours who visited or called in for a visit on a regular basis, informing them on local activities and gossip, was a valuable social contact and support:

> *"My neighbour down the road, she's great. Well real friendly you know. I wouldn't be stuck in her house every minute or nothing like that. Like if she hears anything that's going on around the place she comes up to tell me and she says to me 'how did you not hear about that' and I says 'because you're so nosey you're down there before nine to get all the news'. Ah but I would know everyone in the village like, I'm here so long"* **(038, Mrs Gannon, female, 62 years, Alzheimer's disease, lives with spouse and daughter)**

In other cases it was not just social supports that neighbours provided but in some cases they provided physical care, protecting the individual, particularly when the person living with dementia lived alone:

> *"But I was always leaving the front door open, very much. And emmm, my neighbour, very good this side and this side and all the neighbours, like we all help each other if there's something you know that has to be like something that you can help. And my neighbour Harriet said 'I'll kill ya if you don't stop leaving the door open. Well anyone, you wouldn't have to be (a) retired guard, you could be killed in your house and we won't even know it'. Because it's a different world what we're living in"* **(004, Mrs Beattie, female, 67 years, Alzheimer's disease, lives alone)**

Neighbours also played a role in supporting care-partners:

> *"Interviewer: Would he have a social network outside of the family, you know neighbours coming in, friends coming in? Care-partner: Well there's a friend of mine now that does lunch on a Friday...it would be my friends that I would have roped in that they do odd times and the next door neighbour was very good except now her husband is in hospital, so she's*

> *a bit out of it at the moment. And you know that sort of way. And ah yeah. We go to mass on a Saturday night and everybody comes over and says hello to him"* **(C036, Ms Lynch, female care-partner, daughter)**

> *"Care-partner: Well I have a friend, I have a neighbour two doors down there, Helen, I can talk to her (about her husband's dementia) you know"* **(C034, Mrs Doyle, female care-partner, spouse)**

The role of neighbours in respondents' lives adds to the profile of a care model in Ireland that is largely dependent on informal networks. This is similar to other countries which depend on a familiastic model of care (see chapter three, section 3.12).

In recent years, especially in larger urban areas, the face of communities has changed. Areas that were traditionally older or family-orientated communities are now seeing younger and in some cases more transient populations. The majority of respondents were from these neighbourhoods and the neighbours they once knew well were gone:

> *"Interviewer: Would you have many people that would drop in and out to you, I just met your daughter there? Respondent: Well they're very good, they're great, I have five daughters. Now the neighbours, not a lot now, they used to come in and out more, people are beginning to be a bit more private or something I don't know. But emm they do yeah occasionally yeah and I go into them"* **(035, Mrs Doherty, female, 78 years, vascular dementia, lives alone)**

Where traditionally there would have been a strong sense of neighbourhood/community, neighbours were not around during the day and it was becoming increasingly quiet from morning to evening:

> *"Eh I don't (know) the neighbours here for instance I'd be chatting if they're available. And emm, some*

> *of them are quiet, some of them are, of course at work you know and that would mean I wouldn't see an awful lot of them you know, they're away all day"* **(023, Mr Burke, male, 78 years, Alzheimer's disease, lives with spouse)**

Spending long periods of time at home alone caused feelings of loneliness which were exacerbated by disparate local communities:

> *"I'm starting now to (get lonely), you know, I am starting to, it didn't worry me at all. It's, it's [being alone] beginning to annoy me" (he becomes emotional),* **(030, Mr Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

> *"Well I'm here on my own I wouldn't mind if I had somebody"* **(035, Mrs Doherty, female, 76 years, vascular dementia, lives alone)**

There was a view that as you get older, people lose interest in you, particularly younger people. This view may arise from having poor intergenerational relations and little interaction with younger newer neighbours:

> *"Care-partner: I don't think people even bother to talk to old people. Respondent: The older people even they are lonely, they're on their own. Care-partner: I think the neighbours and all, maybe you'll get it in the odd place the neighbours will go in and watch them an all but other than that I don't think they bother. Interviewer: Because you mentioned that on this road alone there has been, a lot of people have died or houses have been sold... Care-partner: All the old people on this road have died, before then they used to come in and out. Respondent: You never left you're, you never closed your hall door. The hall door was never closed on the houses down here. You didn't have to knock, you'd*

just go in" **(038, Mr and Mrs Gannon, female, 62 years, Alzheimer's disease, lives with spouse and daughter)**

In two cases, respondents had moved away from the area where they had raised their families (in Mrs Lynch's case it was to be closer to her grown-up children and for Mr Doyle it was to move in with his partner):

"Interviewer: And do you have good neighbours? Respondent: Well I don't know much about my neighbours now. Care-partner: You did in W------n you had great neighbours. Respondent: Ah yes, we always had neighbours. Interviewer: Yeah good neighbours. Respondent: Good neighbours, great" **(029, Mrs Lynch, female, 87 years, Alzheimer's disease, lives alone)**

"Nil...I know two people up the road. There's a few around the place, I don't socialise with them or anything like that. There's two people up the road there are good friends of ours, yeah, yeah, I'm satisfied with that...yeah I'm quite happy with that, with the two of them, like for starters they are basically on the same plain as I am, they're not young people or anything. Like young people wouldn't be my thing anymore so...yeah, so they suit me and I suit them" **(034, Mr Doyle, male, 78 years, Alzheimer's disease, lives with spouse)**

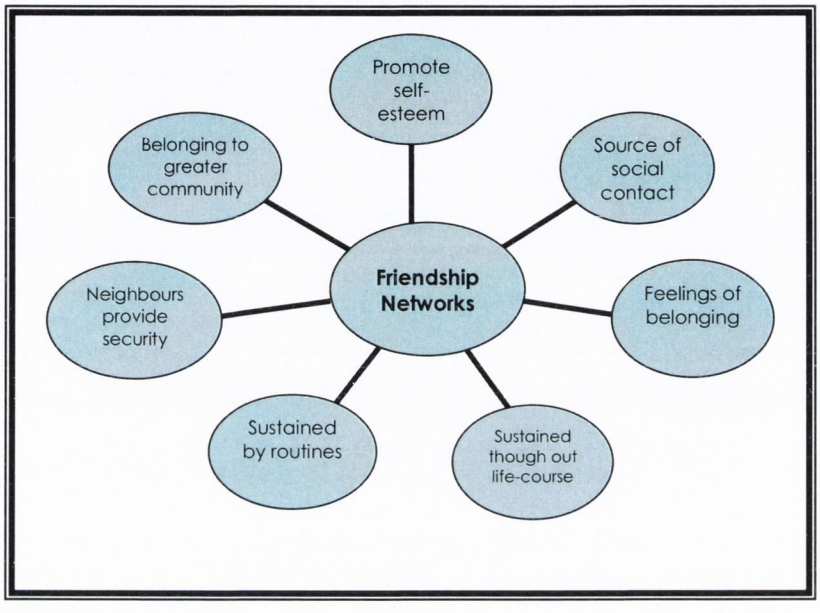
Movement from one neighbourhood to another resulted in poorer social contact within the local community. Having moved relatively recently Mrs Lynch and Mr Doyle found it difficult to develop new acquaintances with their neighbours; it could be argued that loss of confidence and decreased independence contributed to this.

6.3.2.5 Section summary

The data shows how friendship networks promoted feelings of belonging and self-esteem. Figure 6.2 below summarises findings from

this study on the elements and the effect of sustained friendship networks (peers and neighbours).

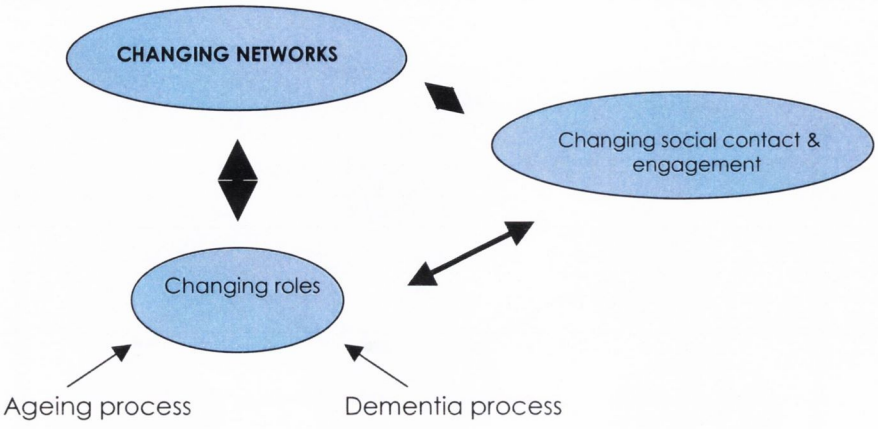
Figure 6.2: Components of friendship networks



Elements of friendship networks included their continuation throughout the life-course, where respondents had friends from their school days and former work colleagues who they kept in touch with. Neighbours too played a role within respondents' friendship networks providing support and maintaining a sense of belonging. These networks were adaptable and changed over time. All respondents were engaged in some social network, and in most cases these were largely family orientated.

An important theme emerging from data analysis in relation to changes in respondents' social networks concerned their changing roles (due to ageing and dementia processes). Changing networks also caused changes in respondents' roles (work, family). In this way, changing networks and changing roles were co-dependent. Changing roles did not always have a negative effect but they generally resulted in a decrease in social engagement and activity, as illustrated by Figure 6.3 below.

Figure 6.3: Interplay between changing networks, changing roles and social engagement



Following the onset of dementia, respondents saw their family members more often than they had in the past and in all cases had more contact with relatives than they had with their friends. This resulted in a greater focus on familial networks in comparison to friendship networks for social interaction and engagement. However, friendship networks offered valuable stimulation and promoted self-esteem and independence. Changes in social networks were found to arise as a result of getting older, processes involved in dementia and environmental/physical factors. Diminishing social networks reduced the availability of social contact, stimulation and meaningful activity.

This section has also shown that many of the changes respondents experienced arose in their view not as a direct result of their dementia. Normal life-cycle changes resulted in smaller social networks, as friends passed away or as work situations, which social networks would have revolved around, changed. In cases where networks were maintained they were primarily focused on familial networks, or continuation of activities.

Loneliness was not an issue many spoke of although a small minority referred to it, particularly the fear of being physically left alone as social networks diminished, or fear of what would happen when a spouse died, fear of becoming isolated. However, it can be argued

that these are fears many people have, regardless of age or memory/cognitive disability.

6.4 Activities

Research has shown that the chances of developing a dementia can be reduced by participating in social activity because it helps to preserve cognitive function (Glei et al, 2005: 870). In fact the study by Glei et al found that activities were more important than the extent of a person's social network in maintaining cognitive function. Whether or not social connectedness or maintained activity can halt or slow the progression of dementia once it starts is a contentious issue. However, social engagement through activity can help to maintain quality of life, promote social contact, combat loneliness and isolation and maintain people living with dementia as active members of society. People can also experience physical, psychological and health benefits from participation in social activity.

In recent years, there has been an increase in the development of activities that are targeted specifically towards people living with dementia. This is drawing attention to the potential and abilities that people living with dementia maintain. Activities can be: (i) therapeutic, for example 'restorative' activity (Pulsford, 1997: 705) such as cognitive therapy, reminiscence therapy, reality therapy, validation therapy, (ii) leisure or social activity where the purpose is to "encourage activity, interaction and enjoyment" (Pulsford, 1997: 706) or (iii) work related activity, paid or unpaid.

It has been shown in an earlier section that social contact can have a positive effect on people living with dementia. In fact some respondents were often 'at their best' in the company of others. The section to follow identifies the types of activities respondents in this sample said they enjoyed. It looks at how respondents participated in activities and the reasons they or their care partners put forward for ceasing or reducing participation. In this way, the research identifies

possible approaches that encourage the continued participation of people living with dementia.

6.4.1 Types of activities

Knowledge of the types of activities that people living with dementia engage in is minimal and fragmented (Marshall and Hutchinson, 2001: 489). Respondents in this study enjoyed many and varied activities, which included both leisure and physical activity but few therapeutic activities[li]. Activities were community based and/or formally organised. Some respondents had commenced activities after the onset of the dementia, while in other cases, activities reflected respondents' lifelong interests. Table 6.2 provides a full list of leisure and social activities undertaken by respondents.

Table 6.2: Informal activities undertaken by respondents

Individual and lifelong activity	Gardening, watching television, reading (newspaper and/or books), cycling, walking, pottering*, knitting, babysitting, sewing, doing the crossword, listening to the radio, painting/drawing, swimming, church related activity,
Group (with one or more other person) activity	Going to the pub, going to the cinema, walking, swimming, attending sporting activities, golfing, shopping, cycling, bridge (and other card games), attending daily mass, crosswords, art classes, holidaying
Organised group activity	Art classes, volunteering, choir.
New activity (since the onset of dementia)	Attending a day centre, walking. Shopping and getting hair done were identified by one respondent as a new meaningful activity
Volunteering	Babysitting, working with the association for the blind, church-related volunteering

* One respondent identified this as an activity

Interestingly, very few respondents took on new activities since the onset of the illness. In most cases, respondents' participation in

[li] Therapeutic activities are not included in these findings and will be discussed in the next chapter.

organised and/or group activities had begun to decline, although analysis of the data showed that solitary activity was quite high. Many respondents undertook activities of a personal interest alone. Their participation in these activities was not dependent on others and they usually carried them out alone, for example gardening:

> *"That's one thing, it's great to get out into the garden"* **(035, Mrs Doherty, female, 76 years, vascular dementia, lives alone)**

Gardening provided meaningful therapeutic activity, brought respondents outdoors and yielded tangible results. Respondents seemed very satisfied that they were participating in individual activities, such as gardening, doing the crossword, pottering.

Many activities had not discontinued with the onset of dementia but how the activitiy was undertaken had changed to accommodate the dementia. For example, Mr Doyle no longer drank alcohol[lii] but he still enjoyed going to his local pub twice a week. He went with his spouse and they met up with people they knew from the local area. Often these trips to the 'local' ended in a sing-a-long but they would head home earlier than they had done previously:

> *"We only drink water with a drop of blackcurrant. We have two pints of water with a drop of blackcurrant in it and we go down maybe about half nine maybe quarter to ten, we go down to our local and there's a sing-along, we go down of a Wednesday and a Saturday. Sometimes Saturdays I don't bother, we might go on a Sunday you know that kind of way, that's it. But we used to go out an awful lot more than that and when we were drinking and that at that time"* **(C034, Mrs Doyle, female care-partner, spouse)**

[lii] Mr Doyle mentioned to that he had been advised by his hospital doctor to give up alcohol. His wife mentioned that he had been a very heavy drinker and they both decided shortly before the interview was conducted to give up alcohol completely.

To illustrate some of the changes experienced by respondents with the onset of dementia, two specific activities will be examined in greater detail: going on holiday and participating in work.

6.4.2 Holidaying

One activity that is lifelong, and can involve other people or be carried out alone, is going on holiday. In this study, the families and adult children of many respondents supported this activity by taking holidays with them. Many respondents were becoming less well able to go away on holiday either alone, or with a spouse and needed the assistance of other family members. For example, Mrs Buckley's and Mrs Doherty's children accompanied them on holidays. Holidaying acted as a retreat/respite for both the person living with dementia and for their care-partner:

> *"No, you see my son has a place down in Spain. And we're planning to go down this year. And the youngest son Sean he's going to come with us. I wouldn't like to go on my own with her just in case. So Sean, Deirdre (daughter) said she might come down for a few days. Sean is definitely coming with us. Once I have him with me I'm OK. We had a great time down there last year"* **(C018 Mr Buckley, male care-partner, spouse)**

For many respondents holidays were very enjoyable but for some changes in the physical environment proved to be too disruptive. For example, Mrs Barry stated that going on holidays was becoming increasingly more difficult as Mr Barry needed more and more physical assistance and for the last number of years they had not gone:

> *"We have a mobile home down in Wexford...and it's got to the stage now that I won't go to Wexford, this is our third year we haven't been, because if that, if those accidents happen down there Emer, I have no facilities... He was good for four weeks and I was saying oh maybe I will, I can drive myself, I have my*

> *own car, maybe I will (go down to Wexford)...I said here I will and the next thing this happens one day (Mr Barry had an incident), the next day, the next day ah two, three days running I said no way, no way could I, I'm back to square one again then, thinking and I was setting myself up for definitely going, definitely going"* **(C032, Mrs Barry, female care-partner, spouse)**

For Mr Martin holidays were not high on his list of priorities:

> *"Holidays is not a priority lets put it that way. It's not that I'm losing out it's just that it isn't a priority"* **(C041, Mr Martin, male care-partner, spouse)**

The benefits associated with getting away on holiday are unquestionable. However, when it became more difficult to go away taking a holiday no longer was perceived as an option. Mrs Barry did not consider going away without her husband and Mr Martin felt the same about his wife. He did not consider taking a break to be a priority. Most care-partners did not express a desire to go away without the respondent, one of the reasons could be attributed to the fact that there was little to facilitate them to do this e.g. formal supports such as respite or grants. Of the whole sample of care-partners, none were in receipt of the respite care grant[liii].

6.4.3 Work-related activity

One female respondent was a volunteer with a local charitable organisation. Nine respondents were retired and seven never worked outside of the home or had worked outside of the home many years ago. Fr Hanrahan was doing a small amount of pastoral work in his local area (mostly holiday cover), although he was on a pension and was not paid for this work. Paid employment was very important to some respondents, particularly the men in the sample (Mr Watts, Mr Burke and Mr Callaghan) even though at the time of interview none of them were in paid employment. Many conversations during

[liii] The Respite Care Grant is a financial State support of €1200 annually provided to informal caregivers who are receiving the Carer's Allowance or Carer's Benefit.

interviews with these men reverted back to topics and themes related to their previous working lives. For these men, their work had a significant influence on their sense of who they were. They had all held responsible jobs and had been very able at them, thus reinforcing their confidence, sense of self and their potential to achieve.

Society places a high value on paid employment. It can act as a source of social capital. Working can be a way of keeping active, included and stimulated. It has already been discussed how Mr Burke felt that his social network had been significantly reduced since his retirement. Mrs Martin felt the consequences of her husband's retirement. She no longer called into her neighbours as often and likewise they failed to visit her as much as before her husband retired. He was now home more often and she was less inclined to participate in other activities and had less contact with other people:

> *"What I think anyway, I don't know if I'd be right or wrong. Like you're not in such connection with people as you would normally be you know, with Paul out now on retirement I wouldn't see the neighbours that much. You know and I think that's a pity too you know. But emm, the same goes for him he would never see the fellas out of work"* **(041, Mrs Martin, female, 77 years, Alzheimer's disease, lives with spouse)**

The opportunity to display ability through paid employment[liv] or conversely to minimise disability diminished with retirement. As Mr Watts describes below, this can affect confidence:

> *"Interviewer: And how would you rate your confidence and self-esteem now? Respondent: Eh, I don't need much confidence now because I'm doing very, very, very, very little now"* **(020, Mr Watts, male, 82 years, Alzheimer's disease, lives with spouse)**

[liv] Greater value is placed on paid employment.

Retirement also meant time available to these older people and opened up new opportunties such as taking on new pursuits such as volunteering. As stated earlier, one respondent was actively involved in volunteering in her local community. It was a source of well-being for Mrs Beattie. Volunteering is recognised as a valuable social pursuit among people of retirement age (Balandin et al, 2006: 677). For people living with dementia the desire to help others in this way does not decrease with a diagnosis (Stansell, 2002: 212). Volunteering focuses on the person's abilities and capabilities rather than on their deficits and need for care (Stansell, 2002: 211). It can give feelings of usefulness, reinforcing positive images of the self:

> *"Respondent: I'd like, my really happy time, the happiest would be to help somebody, help other people you know, be able. You know to be able because I think it gives you courage. Interviewer: What do you mean [by] it gives you courage? Respondent: It gives you courage to know that you're helping somebody, or if they're sad and tell them, try not to make them a bit happy rather than, I don't. I wouldn't really tell anyone if I was sad, I wouldn't want anyone to know in the sense, I'd rather, yeah, I would always rather just pretend as well that I'm fine you know that way. That's the way like. Interviewer: Why? Respondent: I don't know Emer, I really don't. Rather you know. But I would, I know it would be good, it makes me feel really good, feel better in myself if I help somebody else, you know"* **(004, Mrs Beattie, female, 67 years, Alzheimer's disease, lives alone)**

Similarly to the male respondents mentioned above in relation to their previous paid employment, helping others reinforced Mrs Beattie's sense of her abilities and offered her some fulfillment. She had an altruistic response to her situation. Instead of focusing on her disability she preferred to focus on helping others; this in turn may have helped her to cope with her own dementia. MacRae (2008: 407) reports similarly findings based on interviews with eight people who had

early-stage dementia. She concludes that helping others is a way of giving meaning to life and self (MacRae, 2008: 407).

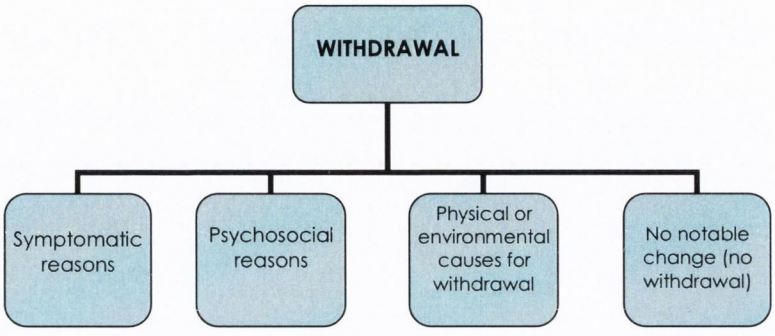
In a study carried out by Stansell (2002) on dementia and volunteering, a number of positive outcomes were identified for people living with dementia. Voluntary work was found to allow the person 'to be how they were', they were helping others. It provided meaning, created feelings of competence and gave feelings of wellbeing. Findings from this thesis are in some ways similar, where it has been shown that respondents strived for meaning in explaining changes but also in their interactions with others e.g. role within kin and peer networks.

Volunteering can be a valuable social pursuit and can reaffirm the person living with dementia as a citizen. The citizenship model asserts that people living with dementia can and do have a lot to contribute and that they also have rights and responsibilities within societal structures (Marshall, 2007). Volunteering encompasses both meaningful activity and a subjective gain for the volunteer. It also reinforces civic responsibility and demonstrates a person's contribution to larger society. Volunteering is a continuation of the life-course, as many people pursue this in older age. As only one respondent in the sample worked as a volunteer, findings here are inconclusive. However, it can be argued that voluntary work has the potential to be a social outlet for people in the early stages of dementia and as such merits further investigation.

6.5 Withdrawal

The majority of respondents interviewed for this thesis withdrew in some way from social participation and social engagement after the onset of dementia. Social withdrawal is common for people living with dementia (Romero and Wenz, 2001: 335). The Figure 6.4 below broadly summarises findings from this thesis on reasons for reduced or discontinued social participation.

Figure 6.4: Reasons for respondents' withdrawal



This model mirrors the psychosocial framework of this thesis where the experience of dementia is a reflection of biological, psychological, physical and social forces. The following section explores this further and examines in detail reasons why some respondents withdrew from activity and participation. Some reasons were associated with the illness trajectory, where experiences of the biological symptoms of dementia meant participation became too difficult. Other reasons for withdrawal were psychosocial responses to having dementia, where external factors and respondents understandings of these affected their participation. Other reasons for withdrawal were based on physical and environmental factors which meant inclusion and participation was too difficult.

6.5.1 Symptomatic reasons for withdrawal

Symptomatic withdrawal occurred when respondents withdrew due to the biological effect of dementia or the symptoms. Examples of symptomatic effects included difficulty in following conversations, word-finding difficulties and disorientation.

(i) Difficulty following conversation

External factors, such as noise or the presence of too many people resulted in some respondents finding conversation difficult to follow and subsequently difficult to engage in:

> *"Emm, up in the golf club it's a noisy enough place, there's three of them in that group and three or four*

> *of them in another group and I'm inclined to look at the television rather than, they're not very interesting anyway I've seen them golfing and the other thing is they stay on and have a few jars you see and they have a lot of talk, whereas I don't drink"* **(023, Mr Burke, male, 78 years, Alzheimer's disease, lives with spouse)**

Mr Burke attributed his lack of engagement, to the fact that he was not part of the golf club drink culture which may or may not be the real reason. This was a common theme across all findings, where respondents sought explanations or attributed meanings to the changes they were experiencing in their lives to factors outside their illness.

Concentration difficulties were also mentioned; respondents found that they were not listening to what was going on or being said around them:

> *"Let me put it this way like at school you know they'd be talking to me about this that and the other, sure I wouldn't be thinking, listening at all"* **(030, Mr Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

(ii) Word-finding difficulties

Although word-findings difficulties were not common for people in the sample, it is a common symptom of dementia and for those who did experience it, the consequences were deleterious:

> *"Respondent: I can see it in my minds eye the words, but I can't get it, it won't come out of my... Interviewer: Mouth? Respondent: Emm? Interviewer: It won't come out of your mouth. And how does that make you feel? Respondent: Ah, sure if you're in company or something like that it, it sort of you'd like to get out of the room and leave me alone. I don't know why"* **(017, Mr Burns, male, 82 years, mixed Alzheimer's disease and vascular dementia, lives with spouse)**

This quote suggests that Mr Burns avoided situations where others might notice his word finding difficulties. Although he says he does not know why he feels like that, this quote suggests that he was embarrassed by how others would view him. The feelings of embarrassment he has are socially constructed as a result of sociological or psychological processes rather than solely as a result of the physical deterioration (Harding and Palfry, 1997).

> *"Respondent: I forget something, if I'm in conversation with people and it goes by and I'm not interested in what they're saying I'm just trying to get my memory back"* **(010, Mrs Curran, female, 74 years, Alzheimer's disease, lives with spouse)**

Mr Burns had severe word-finding difficulties: "trying to find a word makes him (respondent) forget the original question, causing him to get lost within the conversation" **(fieldnotes, 017, Mr Burns, T0, 26/01/06).** When he could not find a word, he laughed, changed the subject or diverted attention to something else. These were coping mechanisms (see chapter 5, section 5.4), making conversation very difficult. He mentioned that some people understood and helped him when he could not find a word, but when people did not do this he felt stupid, like a 'twit'. The reaction of others and his interaction with them compounded negative feelings about himself.

(iii) It's 'too exhausting'

Some respondents stated that since developing a memory problem they tended to get very tired and frustrated in company. Although social activity was a source of stimulation, some respondents needed to monitor how they were feeling and withdrew when the strain of keeping up with conversations became excessive:

> *"He liked, yeah, he loves company you know but not inclined now to and he gets tired you know if he, you see if he can't keep up with what's being said he gets a bit frustrated I suppose you know and then he loses interest in it you know, kind of withdraws from it*

then you know" **(C017, Mrs Burns, female care-partner, spouse)**

(iv) Forgetfulness

Other respondents' forgetfulness was more evident in company than with a care-partner and withdrawal was a commonly used coping mechanism. Mrs Watts said she noticed this at a recent family gathering: those around Mr Watts obviously knew him and engaged with him on a familiar level, yet she noted that he was withdrawing. This loss in recognising others (agnosia) affected his ability to engage and communicate:

"Care-partner: We went up on Monday evening, sure he didn't know any of the family even, my brothers and sisters, you know. He just, the nieces and nephews there like, he wouldn't have [a] clue. And he gets very quiet then and withdrawn, he doesn't talk to anyone when he's in company like that you know. Interviewer: Why do you think that is? Care-partner: I don't know, I think he's afraid really, I think he is, he's frightened like that he should know them and he doesn't, you know" **(C020, Mrs Watts, female care-partner, spouse)**

Respondents who experienced physical disorientation often became more and more reluctant to go out alone (as was shown in Chapter Five, section 5.2.4). If they lived alone or other people did not call to them there was the risk that they could become effectively housebound. In some cases respondents did not go out alone for fear of getting lost or disorientated:

"I have to have somebody with me when I'm going out. There was a time I'd go to the end of the world on my own, not anymore...I would be afraid I would get lost, not knowing where I was and I'd be afraid I would always take the wrong turn, find myself in trouble" **(029, Mrs Lynch, female, 87 years, Alzheimer's disease, lives alone).**

This quote illustrates that Mrs Lynch is very aware of changes that have occurred in her life. She states that she is more afraid; worried that she would find herself in trouble. It is the uncertainty that affects her independence.

(v) Changes in ability

In some cases, not being able to participate in activities at the same level or to the same standard achieved before the onset of dementia caused respondents to completely cease the activity:

> *"Interviewer: You're not as active as you were? Respondent: I'm not? Interviewer: As active? Respondent: Oh no, no, no. Interviewer: Do you mind that? Respondent: I do 'cause I think it's a terrible waste of time. Interviewer: What's a terrible waste? Respondent: Things I could be doing. Such as, can't remember (laughs). Care-partner: She used to love pottering around the garden and that but she doesn't do that anymore. Respondent: And I loved sewing. Interviewer: And you don't do that anymore? Respondent: Very, very little, too frustrating. Interviewer: Why? Respondent: To get everything in the right way, you know, when you're sewing or that. Then when you have, when you find that you have ah, a seam done it's one up beside the other, done the wrong way, you know that kind of way. Interviewer: It's not right, so you don't enjoy it? Respondent: Exactly. It's not together properly"* **(029, Mrs Lynch, female, 87 years, Alzheimer's disease, lives alone)**

6.5.2 Psychosocial withdrawal

Psychosocial withdrawal occurred when people could no longer participate due to psychological or social factors and the stigma of dementia.

(i) Stigma

People living with dementia can try to conceal difficulties they have. Doing this can be stressful and can further contribute to withdrawal (Holmén, Ericsson and Winbald, 2000: 189). A number of respondents and their care-partners spoke about not wanting other people to talk or gossip about them and in some cases this resulted in their severing social contacts.

In most cases respondents and their care-partners were reluctant to be open about their dementia diagnosis with everyone, even if the person living with dementia was personally accepting of their situation:

> *"Well there's no use hiding it, I mean to say obviously I don't want the whole neighbourhood to know"* **(018, Mrs Buckley, female, 79 years, Alzheimer's disease, lives with spouse)**

Although Mrs Buckley was very open about her dementia, speaking about it very frankly with me, the fact that she 'obviously' did not want everyone to know suggests that she expected a negative response from others.

Mrs Doyle's words below reflect the thinking of many respondents/care-partners. The discourse respondents used around dementia and diagnosis gives insight into what they thought about it:

> *"No it's not that, it's kind of if you're drinking in a social environment like on a regular basis do you know what I mean and somebody says 'oh that's terrible what happened to such a body' and you might say to them 'I'm telling you this in-confidence please don't pass it around you know', because you don't want everybody looking at him when he goes in, but the next thing you know everybody, Joe Soap, Joe Soap and people you don't even know, know, you know that kind of way so I don't discuss things out like that. You know I might have a friend that I can talk to, well then that's grand you know.*

> *Because you do need somebody to talk to I know that"* **(C034, Mrs Doyle, female care-partner, spouse)**

> *"The respondent never mentioned Alzheimers' disease to me and when his wife mentioned Alzheimer's it was in a whisper, as if there was a fear around it"* **(fieldnotes, 020, Mr Watts, T0, 09/03/06)**

Closely linked to stigma is embarrassment, as a psychological response to the manifestation of symptoms. For example, word-finding difficulties led to embarrassment, which was experienced less acutely when the social group was familiar and the person felt comfortable within it:

> *"Embarrassing [language difficulties], it's a little bit embarrassing no doubt about it like. But then I'm in a group of people all the time practically you know, we all know each other"* **(033, Fr Hanrahan, male, 70 years, Alzheimer's disease, lives in religious community)**

Similarly, embarrassment was expressed by care-partners when the person living with dementia could not follow conversations:

> *"You know that you feel, you know you're kind've a bit embarrassed at times because, you know in the middle of a conversation that he can't proceed with it, you know. But, after we came home I hardly noticed it at all. When he's in company you notice it more and you see he's a bit bothered which he doesn't admit to, you know but emm but if he can't keep up with the conversation, he gets lost and he'll probably say something out of turn that didn't have any bearing on what was being discussed at all, you know. Just things like that"* **(C017, Mrs Burns, female care-partner, spouse)**

Mrs Burn's embarrassment was due to the social situation rather than the actual symptoms, which did not bother her at other times. Care-partner's embarrassment could also play a part in withdrawal.

Analysis also uncovered an embarrassment in using social services. In many cases where services were available respondents and their care-partners did not readily take them up. It can be difficult for respondents who had never used social services to engage in them in older age. This can affect their participation. Mrs Callaghan was reluctant for her husband to use social services as it made her sad to see her once strong, able and independent husband using them:

> *"I hate to see him go off in this bus, they're all very nice now but like he was a gentleman you know...but kind of going out there with them, you know, with all these people and I shouldn't be like that now, I won't be, I'm not uppish but he, he was a man that did everything, it upsets me you know"* **(C039, Mrs Callaghan, female care-partner, lies with spouse)**

Mrs Callaghan's comments also reflect the fact that she may have felt stigmatised by virtue of using such services.

(ii) Being treated differently

How other people treated respondents also affected their level of participation (see earlier quote from Mr Murphy). Some were aware that they needed to ask a lot of questions to keep up with conversations. They felt more comfortable doing this with a spouse or a close friend or relative, rather than with an acquaintance:

> *"Interviewer: Are you finding that you're losing out a bit in social interactions? Respondent: Yes, I don't like when I have to keep saying what's that, or what's that to anyone, I don't mind my own because they understand you know, they, some of them are the same themselves, they're deaf or something else"* **(010, Mrs Curran, female, 74 years, Alzheimer's disease, lives with spouse).**

This quote by Mrs Curran highlights the respondent's perception of how society views people living with dementia. She felt able to ask questions with 'her own' as they would not draw conclusions about her from her own perceived lack of ability, whereas other people

outside of this close network might. Mrs Curran could also not control how others viewed her, but if they had a close relationship (in the case above she was referring to her sisters) they knew and understood what she was going through and she trusted that they would not think differently of her because of changes in her memory.

Respondents with a high level of awareness of their disability were quicker to identify when they got things wrong and they found that being asked questions made them make mistakes; others could then draw the wrong conclusions about them. This affected confidence and was also very frustrating:

> *"Respondent: Naturally I'm not interested in being quizzed in what day is today (respondent was referring to his medical assessment), I couldn't give a damn what time of the day it is or what day it is, sounds to be a frivolous remark ... not knowing that today is Saturday, or is it? Is it Saturday? Interviewer: No, It's Monday. Respondent: Good, see, I made a mistake. Interviewer: But that's not a worthwhile, it doesn't matter if you make a mistake like that. Respondent: They can form a sort of opinion and there's nobody that can stop it"* **(039, Mr Callaghan, male, 82 years, mixed Alzheimer's disease and vascular dementia, lives with spouse)**

This quote from Mr Callaghan highlights again the lack of control respondents felt over how others perceived them. The judgement of others, in the case the medical profession, was very frustrating for him. It suggests that he feels they did/do not get the full picture when they assess him because the questions they ask are not relevant and do not reflect how he really is.

6.5.3 Physical/environmental reasons for withdrawal

In some cases respondents found activities inaccessible (e.g. attending groups or clubs) because they were presented with physical obstacles and barriers that prevented them from going. The

reasons identified in the data included transport problems, reduced mobility and relying on others to assist them in remaining included.

(i) Transport problems

Where formal activities were available (e.g. day centres, clubs) and where there was a wish to attend, transport to and from the location of the activity was generally needed. One respondent mentioned that he would be interested in attending a Day Centre if he could get a lift to it:

> *"Yeah if it now this is, might say it wrong, but if somebody would bring me up you know, because everything is up at the top of the town, there's nothing down here you know, there are places up there where, for the old and all that sort of thing"* **(030, Mr Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

Family members were generally relied upon to bring respondents to and from activities, as most respondents (N=11) no longer drove.

(ii) Reduced mobility

No longer driving, mobility difficulties, relying on others or poor public transportation were identified as reasons why participation became a challenge. Mobility difficulties prevented the person from doing things, leading to their social world physically diminishing:

> *"Well my social life is in this room, I can't do... (trails off)"* **(036, Mr Moore, male, 93 years, mixed Alzheimer's disease and vascular dementia, lives alone)**

And from participating in physical activity:

> *"I couldn't do it (golfing) because the going up and down hills and all. And I'd never be able to get up the hills"* **(030, Mr Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

Other ailments affected a minority of respondents but also influenced participation:

> *"Now, I do very, very little, with the exception of myself and my wife we go for a walk each day so that I can get a walk in and I, I emm, I have an artificial hip. I used to play a lot of rugby. And emmm, that, the right hip went so I, I walk now with a stick. But other than that"* **(020, Mr Watts, male, 82 years, Alzheimer's disease, lives with spouse)**

(iii) Increased reliance on others

Some respondents were housebound or disinclined to take part in activity unless someone else was with them. A lack of real or perceived independence resulted in withdrawal from activity and participation.

6.5.4 No notable change

It is important to note that not everyone was withdrawing from social networks and activities because of their dementia. Mr Doyle would only withdraw if he was unable to physically continue:

> *"I never think about getting old. It doesn't bother me either at the moment I'm 75 years of age. And I'm active, 100% active. I don't think I could be any better. I have no walking stick or anything, bob's your uncle or...yeah"* **(034, Mr Doyle, male, 76 years, Alzheimer's disease, lives with spouse)**

This quote again highlights the emphasis respondents placed on their physical ability rather than on their cognitive ability.

Some respondents had never been active or involved in the community, and having a dementia for them meant no significant change to their daily routine. Therefore, there can be a high degree of continuity in (low) levels of social engagement and a preference for getting involved in activities should not be assumed:

> *"No, no she's not a social person in so far that emm, even all her life she never liked going out to parties or dancing or anything like that you know. She was an Irish dancer, she was in the Gaelic league, she was in*

> *that, that, that was her circle of friends you know. I was outside of that so (laughs). But emm, that's, that's her social life, she doesn't want a social life herself, this is what she says*" **(C041, Mr Martin, male care-partner, spouse)**

Earlier in the same interview, Mrs Martin stated that since her husband's retirement neighbours failed to visit as much and she did not call to them as often. She expressed some regret and sadness that this social outlet was diminished. In the above quote Mr Martin presumes that his wife does not want a social life of her own, which is not in keeping with what she disclosed to me. This illustrates the importance of seeking the experiences and thoughts of the person living with dementia, not depending solely on proxy measures as the perceived reality can be different to the lived reality.

Other examples of low levels of participation are from Mr Watts who had always depended on his wife for social engagement:

> *"He was born in England and he really only, his friends were over there you know. He never made close friends, they were colleagues, he says they are all dead and they are too I suppose. But he never had close friends, my friends were his friends, became his friends more than the other way around. He didn't have many friends because well his first wife was sick a lot too, so that wasn't easy*" **(C020, Mrs Watts, female care-partner, spouse)**

Similarly to the Watts' Mrs Burke suggests that they never had a large social network:

> *"Interviewer: And do you have a good social network yourself. Like friends and family and things like that? Care-partner: Well I have, I have a lot of family here and we're in touch quite a bit but I wouldn't say we have a great social life in regards going out with other people. Interviewer: Is this a recent change? Care-partner: Well it was always, we were both kind of very busy, when we got to the*

retirement stage and he has been retired since 1991. So he didn't even go to the full 65, he retired at what 62 or something" **(C023, Mrs Burke, female care-partner, spouse)**

6.5.5 Section Summary

Withdrawal from activities was common among respondents because of their dementia. However, decisions to withdraw from activities were not always exclusively based on changes in cognition and memory but were also related to logistic, physical and psychosocial factors. The findings suggest that remaining active and engaged was becoming a greater challenge for many.

However, it should not be assumed that people living with dementia want to be as active as they always were or indeed increase their participation in activity after the onset of dementia. It is important that this is investigated at an individual level, examining individual preferences for inclusion. Findings also show that when meaning is attached to activities there is greater involvement. When they revolve around previous engagement (such as peer/social groups), findings from the data suggest that continued participation occurs more often.

6.8 Chapter Summary

This chapter has explored the social implications of living with dementia, both from the perspective of the individual with dementia and from the point of view of care-partners. The data contains very rich and vivid descriptions of some of the fears, experiences and hopes that the respondents had. The findings show how in general the respondents had experienced a decline in their social life since the time of their diagnosis. Interestingly, the vast majority attributed these changes to normal ageing and to the social adjustments required and expected in ageing such as retirement, and 'slowing down'.

In some cases, the consequences of biological/neurological symptoms affected respondents' ability to engage in activities they had been accustomed to in the past, particularly in relation to leisure activities such as playing bridge, golfing and socialising with others. Psychological responses to having dementia such as fear and reduced confidence resulted in several respondents no longer engaging socially in the same way they had done previously, such as going out unaccompanied.

A major finding of this thesis was the role of the family in respondent's lives. Kinship networks emerged as being extremely important for respondents in this study and were strongly linked to their quality of life. They often contributed to the positive experience of dementia for the person, particularly in relation to spousal relationship. Most respondents continued to have contact with both immediate and extended family. These contacts were daily and sometimes centred around practical tasks, such as running errands for respondents. Where physical care was needed (in the minority of cases) participants were reliant on family members, friends and neighbours for support either to provide this care, coordinate the provision of formal services and/or gathering relevant information for them.

This chapter also portrays very powerfully new findings on how people living with dementias view their world. Some felt guilty about the impact of their dementia and changes associated with it on family members. Increases in dependence combined with changing familial roles (e.g. bread winner, raising children) also influenced family dynamics and respondents' sense of place within them. Respondents' role within the family was very important and something which many wanted to maintain. Maintenance of space and what Hutchinson Leger-Krall and Skodol Wilson (1997) call a Closed Awareness Context (respondents were careful not to divulge the nature and deterioration of their dementia) were common among respondents and their loved ones. An interesting finding was often there was no open communication between care-partners, respondents and other family member about their dementia. Is this

because open communication would have challenged existing roles? Respondents often negotiated a balance to maintain role. The model presented in Figure 6.1 suggests that this balance was enhanced by maintaining space but countered by the family at times reducing independence.

Bell (2004: 23-24) states that communities involve complex social relationships exerting social control, promoting feelings of belonging that support identity and selfhood. Findings from this thesis show that often the most complex relationships were those the respondents had with their children. In two cases where respondents' daughters were the first to notice their mother's dementia, reactions by the two older women were extremely negative. A possible interpretation of this is that it challenged their role in the family and subsequently who they were.

Another feature of complex relationships which is frequently identified in the literature on caring is the development of a paternalistic relationship between caregivers and care-receivers. A lowering of expectations like this can lead to lowered performance and higher dependency, the person become progressively disempowered (Cheston, Bender and Byatt, 2000: 478). As already stated most respondents did not require physical care, an example of paternalism can be found however in a number of cases where care-partners did not want to use the terms Alzheimer's disease or dementia as they thought that it would be upsetting for respondents. It can be argued that these family members were entering into a conspiracy of silence and further contributing to the stigma of dementia in society. However, it should be noted that their motivations were often based on looking out for the other person's 'best interests'; a consequence of this however can be the loss of the other person's autonomy.

Findings from this thesis illustrate another central role of kinship networks was facilitating respondents' continued engagement in activities and their connection to additional social networks. In some

cases care-partners who were spouses found it difficult to take a break or go away on holiday, and this was compounded by the fact that no care-partner in this sample was in receipt of the respite care grant.

In general, the respondents experienced a decline in their friendship networks. Sometimes this emerged as a direct result of their dementia such as no longer going out as much as before in order to prevent their disabilities from being exposed publicly. But in other cases, this decline was perceived to be more closely related to their stage in the life-cycle, ageing and this helped respondents to accept changes such as the death of friend/contemporary, or the erosion of work-related friendships with retirement. Irrespective of the cause, all of the respondents were aware of some degree of decline in their social life/activity.

Friendship networks differed from kinship ones in that respondents did not increase contact with friends as their dementia developed, nor did they begin to rely or depend more on these networks. However, social constructionism tells us we are largely social beings; findings from this study support this view. This chapter has provided valuable findings on the importance of friends for respondents and their role providing stimulation. Care-partners noted the change in their mood where they were often at their best in company that was not kin-related. Friendship networks also helped to maintain self-esteem and reinforced respondents' sense of identity. This finding is very important in light of results from Chapter Five which showed an overall loss of confidence as a result of the experiences of symptomatic change due to dementia. It is indeed unfortunate that whilst visits from friends often brought out the best in people diagnosed with dementia, these friendship networks tended to diminish over time. Friends could also combat the stigma of dementia, for example Mr Murphy went against the norm in relation to normalising and covering up (see Chapter Five, section 5.4.1) as he was very open about his dementia. He had a good and unguarded relationship with his groups of friends. They accepted his diagnosis and did not treat him differently. In this

way they helped him to construct a positive life experience. If stigma is isolation from members of the broader community and a loss of self-respect within it (Sartorius, 2003: 339), Mr Murphy's friends weakened the potential for this.

The friendship networks that were maintained by the men and women in this study were very important and contributed to the positive experience of dementia. In many cases their continuance was aided by routines. These relationships provided valuable stimulation, promoted self-identity and often involved engaging in meaningful activity. The importance and benefits of social contact and engagement is undisputed and often respondents were at their best at these times. How other people acted and interacted with them was reported to have implications on their experience of dementia. As a result, other people needed to accept and facilitate the person's social participation, helping to maintain their identity within peer groups. In many ways this was achieved through treating the person in many ways similarly to how they were always treated. Humour also helped to divert attention from symptoms and was a positive mechanism used in social situations. In situations were respondents' friends accepted the person and did not treat them differently feelings of normalcy and acceptance ensued. The majority of respondents reported positive experiences when they disclosed their diagnosis to friends, as they accepted their changed circumstance. This promoted the development of an 'Open Awareness Context' (Hutchinson Leger-Krall and Skodol Wilson, 1997)

The often undervalued role of neighbours has also been highlighted in this chapter, as neighbours provided social contact, support and care to many respondents and their care-partners. Neighbours calling in to respondents when it became more difficult for them to go out independently provided a sense of connection to the greater community and also played a valuable role in the safety of people living with dementia at home. However, in some cases with gentrification and demographic changes in many Dublin communities, having new and unfamiliar neighbours around meant a

different social culture and way of life. The changing face of communities, in view of the important social and supportive role of neighbours, is a cause for some concern. This shows that there is a need for formal services to provide (some of) the support that local communities and neighbours traditionally provided, such as popping in to make sure that the neighbour is okay and providing some daily social contact. In many cases however, both respondents and care-partners did not want all of their neighbours to know they had were living with dementia and in some cases this resulted in respondents actively avoiding contact with them. This brings us back to the stigma of dementia and the implementation of a 'Closed Awareness Context' mentioned above.

Findings show that respondents enjoyed many social and recreational activities; they did not desist from engaging or participating in these with the onset of dementia. However, in some cases, participation may have decreased or been adapted to facilitate and accommodate dementia. Work-related activity was reported as important for many male respondents. Findings also show that withdrawal from social situations due to symptomatic reasons was common for many respondents. Conversations became too difficult to follow due to excessive noise or the presence of too many people. Agnosia was another reason for respondent withdrawal and the manifestation of word-finding and speech difficulties in company was a source of embarrassment and frustration and caused some respondents to disengage from social contact.

It can be argued that withdrawal was another way respondents attempted to cope. Following a social constructionist framework Sabat (2003) describes the concept of Selfhood as having three elements (Self 1, Self 2 and Self 3). Self 3 provides an explanation of social identity and maintenance of self where the social persona of Self 3 is constructed through what Sabat (2003: 8) calls the "mutual cooperative interaction of persons". Self 3 is the person's socially presented personae and demands interaction with the social world. Findings showed that respondents often withdrew from situations in

which they felt uncomfortable (for instance where they were over stimulated or experienced negative responses from others) and/or situations which they found difficult to control. Control refers to the ability to control how others viewed them and the perceived judgements they felt people would make based on the person's own perceived inability to engage. When respondents were unable to control social situations and how others might view them, they withdrew or no longer participated. Cheston and Bender (1999) argue that social identity is maintained through discursive and other means and many of the 'losses' associated with dementia are attributed to changes in the person's relationships with others, as the person's social persona is constructed through the cooperation of others. This suggests that avoidance as a means to maintain role was a mechanism used by respondents to maintain the status quo and the respondent's social persona. This theme can also be construed as stigma. It prevented respondents from engaging as much as they used to. One woman highlighted her willingness to ask questions and rely on 'her own' but not on those who were not part of her inner circle. To continue participating socially and in activities was sometimes exhausting for her. Respondents wished not to be treated differently and tried to avoid situations where their symptoms would be obvious to others; in some cases this meant avoiding meeting people or not doing activities where there was potential for them to fail.

These findings can be better understood by drawing on the theoretical framework of social constructionism. As a theory social constructionism concerns itself with the self as a social product which can only be understood in relation to its social context (Palfry & Harding, 1997). As Goffman (1966) argues people are social actors, and participants in this research were attempting to, either consciously or subconsciously, present themselves in a way which they perceived others would view as positive. A distinction should be made between the presented self in relation to family and close friends where respondents felt more comfortable and at ease and the presented self to neighbours and other acquaintances.

CHAPTER SEVEN: FINDINGS AND DISCUSSION III: USE AND EXPERIENCE OF FORMAL SUPPORTS

7.1 Introduction

This chapter examines respondents' health and social care needs. It also outlines their use of psychosocial[liv] and formal health and social services. Two research questions are addressed in this chapter, namely i) what are the current service provisions for people living with dementia in Ireland? and ii) how are services accessed?

Data is analysed and presented on respondents' use of services, referral processes and their attitudes to the services they received (primary, secondary and psychosocial services). This places the 'micro' lived experience within a broader socioeconomic and political structure. This chapter also reports data on the diagnosis and assessment of dementia, while also drawing on the literature around best practice in the area.

All respondents in this study were receiving some form of formal community-based care service. They were all attending an Age-Related Outpatient's clinic. Therefore, they had all been seen by a consultant geriatrician. However, apart from this link to the clinic there was a low level of formal service use by respondents. Table 7.1 outlines the services the respondents were using at the time of the interview.

[liv] Psychosocial interventions are "any interventions or technique which intends to enable clients or patients and their families, to live with, manage, bypass, reduce, or come to terms with deficits" (Wilson, 1997: 488).

Table 7.1: Respondents' use of health and social services

GP and Outpatient Clinic	17
Home Help	6
Public Health Nurse	5 (two of these were one-off visits and one respondent no longer receiving service)
Occupational therapy	5[lv]
Day Centre	2
Social Work	1
Private home help	1
Contacted the Alzheimer's Society of Ireland	2 (in both cases this was initial contact and at time of interview they were not in receipt of any ASI services)
Speech and language therapy	1
Private care attendant	1
Meals-on-wheels	1
Physiotherapy	1
Day-hospital	3 (only one of these respondents was still attending at time of interview)
Memory clinic	3
Chiropodist	1
Not receiving any other services	6 (three of these respondents received one-off assessments from PHN or OT and one respondent had attended the Day-hospital)
Currently receiving one service	8
Receiving multiple services	2 (Seven services* and five services** each)
Outlier	Fr Hanrahan lived in a religious community where all his cleaning and cooking were carried out by paid staff. He also had the use of a nurse on call.

*private care attendant, PHN, Day Centre, home help, meals-on-wheels, physiotherapist, attending Day-hospital
** home help, PHN, Day Centre, social worker and OT

The table shows that everybody in the sample visited their GP regularly. Approximately one third (N=6) had a home help and similar numbers (N=5) had a PHN call to their home. Five respondents had availed of an Occupational Therapist. Only two respondents (Mr Moore and Mrs Martin) were receiving a variety or combination of different services. Interestingly, Mr Moore's daughter was co-

[lv] Three of these respondents only received a one-off visit from an OT.

ordinating these services for him. She lived close by and visited her father on a daily basis, involving her friends and neighbours in the provision of additional support for her father. Mr Moore had a Home Help and a PHN calling regularly. He also had Physiotherapy and attended a Day Centre and had meals-on-wheels. Apart from such public and voluntary sector services he also paid for private care attendants. Mrs Martin was the other respondent in receipt of a combination of services. She had Home Help and was attending a dementia-specific Day Centre. She had received an assessment from a community based OT and from a Social Worker. The coordination of Mrs Martin's care was being carried out by a local PHN.

Six respondents (Mrs Beattie, Mrs Curran, Mrs Buckley, Mr Murphy, Mrs Doherty and Mrs Gannon) were not receiving any services apart from their GP and the outpatient clinic. Eight were receiving one service and in most cases this was a publicly provided Home Help (N=4). Interestingly, in three cases respondents had received a one-off visit or assessment by the PHN. In two cases care-partners had contacted the ASI but respondents were not in receipt of any of these services at the time of interview. Section 7.3 expands on respondents' use and experiences of services.

7.2 Service Provision

All respondents were recruited through an Age-Related Outpatients Clinic in a large Dublin-based hospital and consequently they were all using secondary care services. This is not always the case for people living with dementia who live in the community. The sample therefore is likely to be biased with a higher than average proportion in receipt of formal care services. The following section looks at respondents' use of services (core medical and social care services), how they were referred to these services and their thoughts on the services they received.

7.2.1 Use of services

An inclusion criterion for this study was that respondents had to be in good health and in general they were. However, a number of respondents had some minor health and/or chronic health problems. This is relevant as it has been shown in an earlier chapter that often physical health concerns were more important to respondents than memory or cognitive changes.

Table 7.2 outlines the respondents' health conditions (other than dementia), their management of activities of daily living and whether or not they were taking Cholinesterase inhibitors. The reason I included information on Cholinesterase inhibitors is that it is often the only intervention people in the early-stages of dementia receive, particularly as the medical model predominates in the Irish health and social care system.

Table 7.2: Respondents' health conditions, management of activities of daily living and use of anti-dementia medications.

		(no of respondents)
Health complaints and other disabilities (other than dementia)	Mobility difficulties	3
	Hearing impairment	2
	Joint problem (knees & hips)	2
	Cardiac condition	1
	Experienced frequent falls	1
	Asthma	1
	Anxiety	1
	Diabetes	1
	Bladder problems	1
	History of depression	1
	No health complaints	4
Managing Activities of Daily Living	Yes	14
	No	3
Taking Cholinesterase inhibitors (Anti-dementia medication)	Yes	13
	No	4

Chronic illnesses experienced by respondents included joint complaints (N=2) and diabetes (N=1). One respondent had experienced a number of falls in the last few months, which had resulted in hospitalisation on one occasion. In four cases respondents stated they did not have any other health problems.

Respondents' management of activities of daily living was assessed during interviews, as they were asked specific questions about their ability to perform certain tasks (see Appendix C). I collected this data to establish the level of independence respondents had and to gain an accurate picture on changes in their abilities, based also on care-partner interviews as well as the more in-depth qualitative data collected from respondents. Questions around tasks referred to respondents' ability to dress, eat (unaided), walk (unaided), go to the toilet and take care of personal hygiene. Two respondents needed help walking and bathing, another respondent needed assistance dressing. The majority of respondents were managing activities of daily living independently (N=14). Therefore, the level of formal physical health supports needed by respondents in general was not high. This is relevant when we consider the types of interventions that were offered to respondents (see table 7.1 above).

The majority of respondents (N = 13) were taking Cholinesterase inhibitors. The likely reason for this is that they were attending the Outpatient Clinic where it is standard practice to prescribe these medications after diagnosis. It is common for people to experience nausea, vomiting, diarrhoea and loss of appetite as an adverse effect of this type of medication (Miller, 2004: 27). In one case, a respondent had taken a course of Aricept but had had a negative response to the medication and stopped taking them.

In the following section three frequently used services (ASI, PHN and OT) will be examined in greater detail. This will allow for a better picture of respondents' use of these services to emerge.

(i) Alzheimer's Society of Ireland (ASI)

It is interesting that only two respondents were in contact with ASI services. In both cases the respondent's care-partner had instigated the initial contact. However, no ASI services apart from information services were being utilised by respondents or by their care-partners. A reason for this is that services provided by the ASI for people in the early stages of dementia are at a developmental stage, most running on a pilot basis:

> *"Interviewer: Did you get the information from the Alzheimer's [Society]? Care-partner: She phoned me the other day and asked me did I need help. Like at the moment I don't really need help. Interviewer: Has she sent out the information to you yet? Care-partner: She didn't but she said she'd phone on a regular basis to see if I needed, that I could avail of somebody that would drop in here and stay with Amanda for a few hours but that's more or less in case I wanted to go anywhere but like I really don't. I don't have much on at the moment you know"* **(010, Mr Curran, male care-partner, spouse)**

Mr Curran was seeking information about the illness, but he was being offered at-home respite.

In the following case a care-partner, Mrs Burke, had not heard from the ASI since her first contact but she planned to get back in touch with them in the near future:

> *"Interviewer: And you haven't been in touch with the Alzheimer's Society or anything? Care-partner: Well I did ring them on one occasion and they sent me out just some information which was very basic, but I did actually make the phone call, that would be while I was waiting for the brain scan"* **(C023, Mrs Burke, female care-partner, spouse)**

A reason put forward by one care-partner for not contacting the ASI was that they did not perceive their situation as critical. This suggests

that interventions are generally sought when the more severe symptoms of dementia set in. Some also expressed hope that they would never reach that critical stage:

> *"Interviewer: You didn't contact the Alzheimer's Society or the Carers Society? Care-partner: No I don't think so. Interviewer: Would you ever think about contacting them? Care-partner: Well maybe when she gets worse. We're hoping she won't get too bad"* **(C010, Mr Curran, male care-partner, spouse)**

There was also a reticence about contacting the ASI, which may have been linked to the stigma of using such services or an unwillingness to face the reality of the illness:

> *"Interviewer: Did you ever contact the Alzheimer's society? Care-partner: No and I should I suppose really"* **(C020, Mrs Watts, female care-partner, spouse)**

Contacting the ASI had not occurred to some respondents with dementia, largely due to lack of information. Mr Murphy for example did not know who they were:

> *"Interviewer: Did you ever contact the Alzheimer's Society or anything like that? Respondent: Never even heard of them"* **(030, Mr Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

In another case Mrs Beattie wanted to get in touch with the ASI but was waiting for the hospital to do it for her as she lacked confidence and did not feel that she could ring them herself:

> *"Interviewer: And did you ever contact the Alzheimer's Society yourself? Respondent: No, but the last day I was at that hospital, up in -------. The lady doctor, I never saw her before and she was very nice and they really are all very nice and ehh, she said that she was going to contact whatever or whoever and I didn't hear anything"* **(004, Mrs Beattie, female, 67 years, Alzheimer's disease, lives alone)**

In summary the data here show that only two families had made contact with the ASI. In both cases contacts were initiated by care-partners, not the person living with dementia. There was one case where a respondent would have liked to make contact herself but lacked confidence. The data show that where contacts were made, the outcomes were not particularly satisfactory. The Alzheimer's Society was established in the 1980s to provide support to family carers, but in the last number of years they have begun to turn their focus to the needs of the person living with dementia. Therefore, services for those in the early stages are still at a developmental stage. A conclusion can be drawn from the findings that there is greater scope for the Alzheimer's Society to respond to the needs of people in the early stages of dementia. An interview with the CEO of the ASI (discussed in more detail in Chapter Eight) shows, however, that they are making strides in developing services that are inclusive and empowering for people in the early stages of dementia (such as their social inclusion programme).

(ii) Public Health Nurse (PHN)

A total of five respondents had been in contact with their local PHN. There are mental health nurses in the community but none of the respondents were receiving this service. There are no nurses in the community in Ireland that specialise in dementia care. PHNs that called to respondents tended to focus on physical rather than memory and cognitive care:

> *"Interviewer: Has anyone called up from... health services like the Public Health Nurse, or.... Care-partner: Yeah, one, yeah, the, the aftermath of the operation eh, the nurse used to come in regularly"*
>
> **(C024, Mr Griffin, male care-partner, spouse)**

In the above case, Mrs Griffin had undergone extensive surgery and the PHN was calling to provide after-care.

In two cases the contact had been limited to a one-off visit:

> *"She came in the first time when he ret (pause), just the first time and took all the particulars but we*

haven't seen her since" **(C039, Mrs Callaghan, female care-partner, spouse)**

Another interesting case shows how access to services often pertained solely to medical care. A PHN visited Mrs Martin because of a physical health problem, but it gave her care-partner the opportunity to voice his concerns about his wife's memory. This set the wheels in motion for a full assessment and provision of appropriate services (as seen in section 7.2, Mrs Martin was one of two respondents in receipt of an array of services):

Interviewer: And has the Public Health Nurse been in to see you? Care-partner: She has yes, she ...Interviewer: Was that over Tina's knee that she came in? Care-partner: She came over the knee and I told her about her memory, so ehh yes she is aware of it like you know. She's checking up on emm, at the moment she, I think she's on holidays but the last time we saw her she was ehh checking up on facilities that are available, that we might need to use, you know" **(C041, Mr Martin, male care-partner, spouse)**

This quote also shows that people living with dementia and their care-partners do not or are slower to contact social or health services over cognitive and memory changes. As the system of care is heavily medicalised, it suggests that people need a physical manifestation of ill-health before seeking assistance.

There was also an issue around service continuity. In Mr Barry's case, once the PHN retired the service was discontinued and he did not receive this service from anyone else:

"Interviewer: Would you ever see the Public Health Nurse? Respondent: She used to come in here twice a week and then she stopped altogether. I think she retired, Áine something is her name" **(C032, Mrs Barry, female care-partner, spouse)**

In another case, a care-partner was aware of the PHN service and clearly felt they could have benefited from it but had not been referred to the service. Mr Curran would have liked the PHN to call regularly to see his wife. He saw the PHN service as reassuring, providing them with regular contact with the health services:

> *"Interviewer: Why would you like the Public Health Nurse to call? Care-partner: Just that if, if she was calling to see her, I don't know how often they call, maybe weekly or fortnightly or whatever. If she was calling on that basis then maybe she would be calling between our three-month visits to the GP, perhaps take blood pressure or something like that or check with her. And if the service is there we'd like to avail of it, you know what I mean...well I did hear there was a nurse available in the area and that she would drop in on a regular basis, we haven't actually had a call from her yet. But anything like that, that would be available, keep us up-to-date on what's going on, would be quite handy you know"* **(C010, Mr Curran, male care-partner, spouse)**

Mr Curran's wishes were echoed by another male respondent, Mr Watts who had Alzheimer's disease:

> *"Respondent: I do, I feel that we should have somebody who, who, when you get to the age that I am, I will be 82 in June. And I reckon there should be somebody coming round checking on you. But there is nobody. Interviewer: Do you think that should be a doctor or a nurse or a community worker or...? Respondent: Well I think it should be somebody who would have the idea that they would be checking on you to see you were doing the right things"* **(020, Mr Watts, male, 82 years, Alzheimer's disease, lives with spouse)**

We have seen already that people often wait until a critical juncture before seeking interventions, or do not seek assistance even when they are aware that they should seek and could benefit from it (see

quote from Mr Martin above). Therefore, Mr Watts' suggestion has great relevance for attempts to develop services that reach out to people living with dementia.

There was also a perception held by some that the PHN service was over stretched:

> *"Interviewer: He mentioned that the Public Health Nurse used to call. Care-partner: Oh for God's sake, those girls are run off their feet. They are run off their feet Emer. She told me she has three hundred and something houses to do. I mean she said if I ever want her to ring her, but try to ring them and see how...(trails off)"* **(C032, Mrs Barry, female care-partner, spouse)**

Overall, the Public Health Nursing service was very important for respondents and for their care partners. Where the service was available and accessed, PHNs provided reassurance and regular contact with health services. They were also significant for referring respondents to other services. However, the service was perceived to be over-stretched and when PHNs failed to call out to homes there was a reluctance to follow this up. There is also a question around the appropriateness of the PHN service in addressing the needs of people living with dementia, particularly as the illness has wide-ranging psychological and social implications, as shown in Chapter Six. For many people with early-stage dementia (and for virtually all of the respondents in this study) medical needs are not high. The role of the PHN for respondents in this study, in its current form, as an intervention for those with dementia is not that appropriate as they role remit is to provide physical care. The PHN service however was instrumental in referring people on to other services e.g. social worker for Mrs Martin.

(iii) Occupational Therapy (OT)

The medicalisation of dementia and the way in which community care services appeared to focus on physical health rather than on memory, cognitive, psychological and social needs were also

evident in the data collected on occupational therapy. For example, in Mrs Martin's case the OT called because the respondent had a bad knee, not because of the respondent's memory/cognitive disability:

> *"Interviewer: And [the] occupational therapist has been out to see you or anything like that? Care-partner: Yes, from the Clinic in ------- road. She came out I think it was to do with Tina's knee more than it was with anything else"* **(C041, Mr Martin, male care-partner, spouse)**

Key services provided by OTs were assessment and the provision of home adaptations:

> *"Interviewer: Have you had any adaptations made to the house to help you, like a rail put on the stairs? Respondent: There's a rail on the stairs, put on about a year ago, it's [a] great help getting up and down the stairs. And emm, there's a thing on the side of the bed, a half rail helps me get in and out of bed"* **(032, Mr Barry, male, 70 years, Alzheimer's disease and vascular dementia, lives with spouse)**

As the waiting list for public provision was too long, in one case the OT service was bought in privately. Mrs Barry had been advised by an administrator from her Local Health Office to pay for this service privately:

> *"We got an occupational therapist; we paid her privately because they [Local Health Office] said it would be quicker to get things done"* **(C032, Mrs Barry, female care-partner, spouse)**

Waiting lists are often mentioned in the media, but none of the respondents in this study complained of having to wait long for auxiliary services. However, an important explanation for this is (as can be seen from Table 7.1) the fact that they were not receiving many of these services:

> *"Interviewer: And did you have to wait a long time for that (OT assessment)? Care-partner: No, emm surprisingly enough there was only a couple of months, I think they could see it was, it was badly needed you know"* **(C029, Ms Lynch, female care-partner, daughter)**

Whilst only three respondents had an OT call to their house for assessment, two respondents had regular contact with an OT as they had or were at the time of interview attending the Day-hospital where this service is provided. In these cases attendance at the Day-hospital spanned a number of weeks. Mrs Beattie received memory support and training techniques which worked very well for her:

> *"Respondent: But you see I write down all the things, this is the memory calendar (takes down a calendar that hangs by the phone with all her appointments written on it). Oh I learnt this down in the occupational therapy. Interviewer: You went to occupational therapy? Respondent: Oh I went for thirteen weeks up in ----------, day care. Day care centre yeah. And very nice and learned how to do the phone for to make different markers, with a line say for three numbers and then a line and so many and then the line, it helps to hold it in front of you like that rather than, because you would have to try maybe like seven times to do the number I wanted and they taught you that. And also, speech therapy because when I got not well in the beginning I was mixing up say only for an instance if there were only four or five words in a little sentence I was saying the last word first and mixing it all up, that's the truth. Interviewer: And they sorted that out for you? Respondent: Ah no, they helped me. Ah yeah, they helped me they couldn't sort that out when you have dementia, Alzheimer's. They couldn't but they helped me to cope, do you understand"* **(004, Mrs**

Beattie, female, 67 years, Alzheimer's disease, lives alone)

Mrs Beattie met with an OT regularly for ten weeks. Her words in this quote are powerful as they reflect insight into her own problems, her acceptance of these and the way in which occupational therapy can benefit a person in the early stages of dementia.

Similarly to the PHN, the role of the OT was generally in response to physical need and assessment, emphasising the introduction of home adaptations. In the only case where memory training and memory support techniques were offered, they worked very well.

7.2.2 Referral pathways

The early diagnosis of dementia is strongly advocated in the literature (O'Shea and O'Reilly, 1999: 43). The argument in favour of early diagnosis centres around the benefits derived to the individual. Yet what happens once this diagnosis is made? Best practice contends that early diagnosis results in early referral and subsequently in earlier interventions. The process of appropriate referral is important, particularly if effective interventions are to be implemented at an early stage. As the data has shown already, all respondents had been referred to secondary care services (Hospital Outpatient Clinic). Table 7.3 gives a break down of the referral sources to these services.

Table 7.3: Sources of referral to Outpatients clinic

General practitioner	11
Another hospital consultant	3
National memory clinic	3

All respondents had been referred to the Outpatients by a GP or through hospital consultants or memory clinics. The other main service providers to carry out referrals included the hospital Outpatients clinic and the PHN. The hospital was not only a place for service provision but also a place where respondents received further referrals to outside services. The following section addresses these issues.

(i) Hospital referrals

In the following case Mrs Curran was referred to the Public Health Nurse by the liaison nurse from the Outpatient Clinic. The importance of this referral is highlighted by Mr Curran, he would like the nurse to call regularly:

> *"Care-partner: Actually, she got in touch with that nurse to get in touch with us but eh, I would like that [Public Health] nurse to call on a regular basis if she is in the area. And she did phone us, but the day she phoned we were on our way into the clinic and we told her that we were on our way into the clinic"*
> **(C010, Mr Curran, male care-partner, spouse)**

As stated earlier many respondents valued having regular contact with health service professionals but accessing Outpatients could be laborious and resources were often stretched. In Mrs Lynch's case her daughter had to insist that her mother remain a client of the clinic, despite the doctor wanting to discontinue the respondent's attendance. This quote also illustrates the often arduous process involved in receiving a referral:

> *"Interviewer: And how do you find them up in the hospital? Care-partner: Oh I find them very good, very helpful, now you know emmm....but sometimes I feel like I'm sitting there and I'm telling them that you know, that sometimes things are disastrous you know and ehh 'oh that's fine, oh we'll see you in six months' or see you in three...Oh I mean there was actually one time emmm the doctor said to me now I don't know who he was, he was a young man and he says 'oh that's grand I don't think we need to see your mother anymore' and emmm and I was kind of sitting there 'what' and he said 'ah everything is fine', so I said, well he says 'well if you find things progress again, emm you can always come back to us'. So I said 'hold on, does that mean that I have to go back through all the red tape again and go to*

> *the GP and being referred up here and go through all that procedure again' and he says 'ah yeah' and I says 'no', I said 'I'll be back in six months. I said I'm not going through that again'"* **(C029, Ms Lynch, female care-partner, daughter)**

This also illustrates the lack of services for people living with dementia. The one service they were receiving, although not rehabilitative and in the doctor's opinion not necessary, was very important to the Lynch's.

(ii) PHN referrals

Availing of one service often had a snow-ball effect insofar as once familiar with the person's circumstances, health service professionals often referred these people on to other service providers. In the following case, the PHN organised for Mrs Martin to attend the local dementia-specific Day Centre:

> *"Interviewer: And when the Public Health Nurse came into you? Did she visit often or did she come in once or twice? Respondent: I think it's twice now we're seeing her. But emm she told me about the, about the club down there and that, so I went down and all people like yourself grand so ehh I would go to that because it's in the area. Well the two of us went the last time* **(041, Mrs Martin, female, 77 years, Alzheimer's disease, lives with spouse)**

Data show how in the early stages of a dementia, the Public Health Nurse played a key role in referring respondents to other service providers. However, there was no continuous assessment or monitoring where the person and their care-partner were in contact with the same service provider throughout the illness (other than their GP and the hospital outpatients). Only in one case was a respondent in contact with a non-medical service provider i.e. a community-based social worker:

> *"Interviewer: And has the Public Health Nurse come into you at all? Care-partner: Emm, she, at the*

> *beginning yeah. When it all started and ehh and just getting things up and running you know"* **(C029, Ms Lynch, female care-partner, daughter)**

(iii) GP referrals

In general, the respondents had a good relationship with their GP and had regular contact with them. However, it is interesting to note that in two cases it was not respondents' own GPs that made the referral to the Outpatients clinic but one of their children's GP.

In three cases GPs initially referred respondents to a national memory clinic and from there they were referred to hospital Outpatients:

> *"Care-partner: Yeah, emm, we, I talked to her GP about it and ehh he said right, he said we'll just send her, I think they sent her for tests, memory tests and all this sort of thing and then she was referred to Professor ------* **"(C029, Ms Lynch, female care-partner, daughter)**

(iv) Not accepting referrals

Interestingly, the data show how referrals to other service providers were sometimes offered but not readily taken up, as care-partners and respondents did not perceive their situation as significant enough for this type of intervention. This was a common theme; people were reluctant to seek interventions and waited for critical incidences before doing so:

> *"[The consultant] did have a chat with me one day and said that there is services available, there's the nurse and there's also day care if we wanted to avail of it and he made me aware of a few things that if I ever need them they are available. At the moment I didn't really feel the need for them, you know... Well we don't really use any of them (community care services) at the moment. But I'm only aware now that they are there. I wasn't aware of what was*

available at the time, because it's kind of new to us"
(C010, Mr Curran, male care-partner, spouse)

This quote is interesting on two levels. Firstly, it highlights the lack of appropriate interventions. Are people waiting for critical incidences because what is provided does not meet their needs? Mr Curran's words also reveal the fact that many people in older age have never used services, they do not know what is available and this can make them reluctant to use services. There can be a stigma attached to availing of State benefits and services, particularly if they are linked to mental health or age-related services.

Others believed that services, particularly voluntary services, would be sub-optimal in quality and were somewhat scathing about these:

"Interviewer: And are you getting any kind of help into the house, like home help or a carer to help you out? Care-partner: No. You see Emer, you might think this is odd, Jean (daughter) says if you look for help I would die if say I know there's neighbours around there that does caring and there's one particular one and if she knocked at the door I'd laugh, because she can't care for herself never mind care for other people, how she does it is beyond me and get paid for it" **(C032, Mrs Barry, female care-partner, spouse)**

Mrs Burns again highlights the lack of appropriate interventions:

"Interviewer: And do you think that current community-based services are appropriate for both of you? Care-partner: We don't use them, we don't, we haven't had the need, we haven't needed them yet. You know, as long as I have my health, you know I'm 78 years of age now thanks be to God I have my health, you know as long as we can cope. We can cope pretty well thank God" **(C017, Mrs Burns, female care-partner, spouse)**

Mrs Burns also wants to take responsibility for her husband's health and care. She focuses on her own health rather than her husband's health in this quote suggesting that as long as she can provide care she will. Interviews Mrs Burns and her husband showed a warm and loving connection; she speaks about their ability to cope which creates an image of togetherness. Mr Burns cared deeply about his wife and expressed feelings of guilt that she had to assist and help him. He became emotional during one interview when talking about all she did for him. This data is indicative of the strong informal care ethic that prevails in many families, not in the least as a result of the lack of or perceived poor quality of formal services.

(v) Self-referrals

Data also show how in some cases people were often not aware of what services were available to them and what they were entitled to; therefore they were unable to self-refer even though according to the Department of Health and Children people can access services through self-referral (Department of Health and Children, 2001a: 15). Information was often garnered from other people's experiences rather than directly from health and social care service providers:

> *"I applied for, I didn't know there was such a thing Emer (carers allowance) and somebody said to me you're mad not to apply for that"* **(C032, Mrs Barry, female care-partner, spouse)**

> *"I remember mentioning to some people is there, can there be training for us and I didn't get any place. Of course I knew cousins of mine down the country had gotten training when their mother was bed bound and you know nobody had ever suggested, I asked her and I got no, no further and nobody since then has said about it"* **(C036, Ms Moore, female care-partner, daughter)**

Advice given to one respondent by a HSE administrator was based on the HSE employee's own experience and not the standard

information-giving practice of the health service. It also shows that people had to resort to privately paid services in the absence of sufficient public services:

> *"Interviewer: A lot of information you're getting then is from friends or word of mouth or telling you that [the] waiting list is really long? Care-partner: Oh they told me on the phone her own mother got it, she was out of ----------, I don't know why she was talking to me, but she told me herself her mother was waiting and she got it [house adaptations] done herself. Interviewer: This was a service provider? Care-partner: Yeah. She said, I said 'ah no', she said 'forget that', it could have been when Seamus was up at one of the clinics now Emer, could have been after that, we're thinking of getting it done, says she 'my mother got it done herself because I believe there's a waiting list of two years'"* **(C032, Mrs Barry, female care-partner, spouse)**

A difficulty with this word-of-mouth dissemination of information was that some people found out about services and others did not. There was a lack of formal information provision about services and entitlements:

> *"I think the State is failing in not letting people know all of their options without them having to find out you know. I think it's a bit, a bit much you know for a person say now, I'm, I'm fairly alert I think you know but ehh I think we should be notified as to what is available. And there should be no hassle you know what I mean. It's hard enough dealing with the day-to-day situations at home without having to emm start looking for information"* **(C041, Mr Martin, male care-partner, husband)**

Mr Martin's words here are quite powerful as they highlight the discrepancies and inefficiencies of the current system of health and

social care which can add to the worry and strain experienced people living with dementia and their carers.

> *"Interviewer: And respite care or anything like that, you know the respite. Are you getting your respite care grant? Care-partner: I never even heard of it"* **(C029, Ms Lynch, female care-partner, daughter)**

Accessing information about referrals to specific services can be difficult, particularly for those in the very early stages of dementia who are not orientated to the system of care:

> *"I wouldn't know what information to look for. It's one of these things you know that you know nothing about it"* **(030, Mr Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

Mr Murphy had received a diagnosis of dementia a number of weeks before this interview. On the one hand, he was only coming to terms with his diagnosis when I spoke to him, but on the other hand he had been given little information about his diagnosis at the time.

As it was a new situation for people, it took some time to process information:

> *"Interviewer: And do you think at the moment community-based services are adequate for you both? Care-partner: Well we don't really use any of them at the moment. But I'm only aware now that they are there. I wasn't aware of what was available at the time, because it's kind of new to us"* **(C017, Mrs Burns, female care-partner, spouse)**

Respondents' referrals were mainly made by their GP, PHN or through the Outpatient Clinic. As dementia was a new experience for people, they sometimes did not know where to look for information or where to access services. When this occurred the task of making the referral fell to others.

7.2.3 Attitudes to services

The following section examines respondents' views on the services received by them and by their care-partners. In general, they were well placed to comment on current systems as they were all connected into this system through a hospital Outpatient clinic. Findings from this thesis have further highlighted the reliance in Ireland on the medical model of care. Therefore, this section takes a medical slant, focusing primarily on core medical services such as GP services and the Outpatient Clinic. Other aspects of service delivery which respondents and their care-partners expressed strong views on were private care and transport to and from services.

(i) General practice

In most cases respondents were very happy with the GP services they were receiving. They tended to have a personal relationship with their GP when compared to the relationships they had with other service providers; this was possibly due to the long-standing nature of the GP/patient relationship. Often they called their GP by his/her first name, talking about them in a familiar manner:

> *"Michael (their GP) is a lovely man, he's you know, if you want anything he'll refer you if you need it"*
>
> **(C017, Mrs Burns, female, care-partner, spouse)**

Mrs Burns quote also highlights the power imbalance between the doctor and client: the doctor holds the information to identify and the power to refer her husband to another service. Issues around information resonate with aspects of the citizenship model where the person can neither be empowered nor in position to improve their status or position if they do not have basic knowledge about the illness or services and interventions available to them.

> *"Interviewer: Would you see your GP regularly? Respondent: Yep. In the pub. He goes to the same pub as me. But I only go on Friday and Sunday you know. Interviewer: And would you have a good relationship with your GP? Respondent: Great. Interviewer: And is that important? Respondent: Yeah*

because I can ring him, I ring him" **(030, Mr Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

Mr Murphy identifies with his GP as being similar to himself. This familiarity supports his relationship with the doctor and hence the imbalance is somewhat lessened.

Like PHN services, GP services were viewed as over-stretched:

"Interviewer: And would you have a good relationship with your GP? Respondent: Ah yes, he's a busy man of course and emm, the visits are short but they were grand enough because I hadn't any complaints" **(023, Mr Burke, male, 78 years, Alzheimer's disease, lives with spouse)**

Mr Burke does not identify visiting his GP with his memory and cognitive disability. This could be because his GP does not provide him with what he needs.

A practical difficulty expressed by two people about the local GP service was their failure to provide an adequate home visiting service:

"They don't come up here you know, you know the way they will, years ago they used to come up to the person's house and ask them how they're doing, or if they're in the area they'd come up and see you but they don't do that anymore" **(010, Mrs Curran, female, 74 years, Alzheimer's disease, lives with spouse)**

This was a particular problem for Mrs Moore whose father used a wheelchair:

"Interviewer: And would he see his GP often? Care-partner: No. Interviewer: No? Care-partner: He gets a three months prescription and then he got to the stage when she said 'you know you don't need to bring him', because it is a trouble bringing him up and she won't come out to the house and if there's a problem eh, it's a case of 'can't you bring him up' and that means I put him in the wheelchair and

> *wheel him up. She is only up M------- road but that's the story, you wheel him up"* **(C036, Ms Moore, female care-partner, daughter)**

Tied to an earlier quote about access to secondary care services, this doctor too does not see the benefit of continuous visits to their service by the person living with dementia. In Ms Moore's case it is physically very difficult for her to bring her father up to the local GP surgery but she continues to do it because she feels it is of value. In this respect, she resembles Ms Lynch who insisted with the outpatient doctor that her mother continue to attend.

(ii) Outpatient Clinic

High levels of satisfaction with the Outpatient Clinic were also expressed:

> *"They're very good in the hospital. We find them extremely good down there, very kind and that nurse calls out now when she needs blood taken or anything like that before a visit and does everything like. I didn't think there was such a service. You hear so many people running the services down here and we found since anytime we've been to ---------- they were so good like we couldn't believe it like"* **(C010, Mr Curran, male care-partner, spouse)**

However, it was noted that the clinic was extremely busy:

> *"Well they [staff at hospital clinic] were very busy now the second day. Em, but still it was quite efficient now really. I didn't feel quite comfortable as well. Eh, but like all those places they are busy, I don't know what they can do to, it's just I suppose, especially older people, there are lots of older people that I would see there and I'm sure there's a lot of problems with them"* **(023, Mr Burke, male, 78 years, Alzheimer's disease, lives with spouse)**

Similarly to the PHN service, it was important for care-partners to have regular contact with medical professionals at the Outpatient Clinic as this contact gave them reassurance:

> *"Well you see, well he was in hospital. He's getting what he needs and I'm delighted now that Philip (son) got him into see Dr. ---------- you know because I'll be glad, you know he's not going to improve and as he dis-improves you'll be glad to have that or whenever and you know if he was really bad I'd be able to call on them which would, I wouldn't have any hesitation about calling them, if I felt it was getting beyond me "* **(C017, Mrs Burns, female care-partner, spouse)**

This was a reality for many respondents, although continued treatment or attendance at the clinic was not guaranteed and was more dependent on the presence of physical care needs, which again follows a heavily medical model:

> *"The hospital said now that they don't want to see him, so whether we hear anything from -------- (another hospital) I don't know. So other than that now, we're just... (trails off)"* **(C032, Mrs Barry, female care-partner, spouse)**

The fact that the clinic was consultant-led was also mentioned, and this was a source of reassurance but also of frustration:

> *"The last time we were up we had a male doctor and we went through the things bla, bla, bla, tick, tick, tick, out. ---------- [Consultant] comes in and shakes your hand, I mean one of the old people said that to me once, 'ah I have to hang around now' she says, 'and what am I hanging around for, the handshake'. They know it. We were there for two hours waiting for our appointment, because neither of the consultants had turned up. Now I think that's an awful lack of consideration for the patients, they're all old people and that's not the first time that*

has happened. That, that annoys me, I think that's an awful lack of respect for people" **(C036, Ms Moore, female care-partner, daughter)**

Waiting times at the Outpatient Clinic were far too long for many older people attending. Ms Moore reiterated her point in the following quotation, however she also mentioned that one of the doctors remembered her father from the Day-hospital. This was important as frequent contact with the same service provider helped to build rapport and trust:

"Oh we don't see the consultant except that he comes in to shake hands with us at the end. And I don't want to shake hands with him particularly, do you know what I mean. That's the level of, but some of the ones on the ground, like that lady (doctor), she was really concerned and interested. She knew him from the Day-hospital and she was very anxious to see what she could do for him you know" **(C036, Ms Moore, female care-partner, daughter)**

(iii) Private care

Some respondents opted to buy in and pay for extra supports privately as public services, such as home help and care attendant services, were in short supply and failed to cover weekends or evenings and nights. This often meant that families had to step in to provide or coordinate care:

"He gets home help and he gets carers coming to wash him in the morning, emm, the problem with State help, I mean it's great, but like it's obviously only weekdays. And like there's a letter there today to say now there's no home help for two weeks during the summer and there's never home help during bank holidays or weekends or any of those times you have to get private help in. But we're really lucky we've got somebody that will come, she even comes Christmas day to get him washed, she's great

now, she really is" **(C036, Ms Moore, female care-partner, daughter)**

This quote shows how the extent and quality of services is often dependent on the subjective nature of the provider. Mr Moore's home help does different hours than she is required to do, coming on Christmas day for example. Historically, there has been a dependence on families to provide care and this informal care model has perpetuated into the 21st century (see Chapter Three for a further discussion on health and social care policy in Ireland). While very few respondents required the level and extent of care that Mr Moore did, his situation supports Convery's (2001: 83) assertion that "although adults are not legally obliged to care for their parents or other elderly relatives, there is an implied moral obligation placed on them to do so".

(iv) Transport

In Chapter Six, section 6.6.3, transport was identified as a barrier to attending social activities. Transport to and from service provision sites was also a problem, particularly the inadequacy of public transport services:

"But the emm, I don't know if there's any point saying this to you the, the, transport to the hospital is private transport and I don't know now what you think but the, they don't take the wheelchair. So Dad has, we take him out to the front door, out there and he has to get into that bus. OK he's helped but I don't, I think it's, on a Monday from [Day Centre] they have a bus with a lovely lift, wheel on and up, I think that's (hospital transport arrangement) ridiculous, a man in a wheelchair" **(C036, Ms Moore, female care-partner, daughter)**

"We get a taxi here and there if you want to go somewhere up to the hospital or that and I mean that's the way to do [it]" **(C039, Mrs Callaghan, female care-partner, spouse)**

When transport was provided by the service provider, there was little flexibility, which did not always suit the person living with dementia:

> *"You know you have to be on your toes, be ready when they're ready to collect you. You get your dinner and all up there, well you get your dinner, cup of tea"* **(032, Mr Barry, male. 79 years, mixed Alzheimer's disease and vascular dementia, lives with spouse and two children)**

For Mr Barry the inflexibility of the transport arrangement was another reason he did not like attending the Day Centre, he found it stressful having to be under pressure to be ready to leave at a specific time.

7.2.4 Section summary

In general, the findings show that respondents and their care-partners were happy with the services they were receiving. However, most used few services and for this reason thoughts and comments on services generally centred on GP services and attendance at Outpatient Clinics. The main issues raised were time constraints customary in the GP services and the strict Consultant-led approach in the Outpatient Clinics. A key issue for some was transport to and from services: this ties in with the lack of home visits by GPs and the inadequacy of transport to Day Centres and to the hospital.

Findings from this thesis further highlight the strong reliance on the medical model as a framework for health and social care in Ireland. Despite, in some cases, doctors' reluctance or perception that their service did little to meet the needs of the person living with dementia; several care-partners were determined to keep the person living with dementia linked in to these services, largely because it offered reassurance and was the only tangible source of external assistance available. These situations also highlight the lack of appropriate interventions available to respondents.

7.3 Diagnosis and Assessment

The following section examines respondents' experiences of assessment and the disclosure of their diagnosis of dementia. It has already been mentioned that not all respondents received a formal diagnosis but were told they had a cognitive and memory impairment. This section also presents data on respondents' experiences of being assessed for services following diagnosis. The debate around disclosing a diagnosis is still very contentious and remains unresolved. Therefore, before findings are presented on diagnosis, a review of the main issues around disclosure is presented.

7.3.1 The disclosure debate

It is more likely that people will receive a diagnosis of dementia now compared to a number of years ago. This is partly due to the fact that dementia is no longer viewed as a normal part of the ageing process. Recently, there has been a change in thinking around disclosing a diagnosis to the person living with dementia. It is now felt that people should be told at the earliest possible time, unless there are medical or social reasons for holding back this information (O'Shea and O'Reilly, 1999: 22). This shift has moved practices in disclosure away from those once rooted in the ethical principle of beneficence which is to do no harm, towards the principle of autonomy[lvi] which is to respect the person and their right to self-determination.

There is little evidence to support suggestions that people who are made aware of their diagnosis suffer irreparable or long-term harm (Pinner, 2000: 517). It is seen that there are benefits to disclosure and it is strongly recommended that practices should be improved around early diagnosis, as there are considerable medical, social and psychological benefits to early diagnosis (Wilkinson and Milne, 2003: 302).

[lvi] Pinner and Bouman (2003: 336) see this as a moral debate, centred on respect for autonomy (the ability to self-govern and make one's own choices) and non-maleficence (not inflicting harm intentionally).

The parallels between disclosing a diagnosis of cancer and dementia are referred to extensively in the literature (Keating et al, 2005; Pinner, 2000, Rice and Warner, 1994). In recent years with the advancement of cancer treatments, there has been a dramatic change in attitudes towards the diagnosis of cancer. However, this 'progression of openness' (Pinner, 2000: 514) has not been mirrored in practices around diagnosing dementia. Disclosure can depend on (i) the family's preference (Maguire et al, 1996: 229) (ii) difficulties in determining an accurate diagnosis (Rice and Warner, 1994), (iii) medical professionals' wish to protect the person, as it is perceived that there are few therapeutic interventions after diagnosis (Cahill et al, 2006: 319) and (iv) an attempt to avoid distress, where distress can be in the form of reducing hope, creating unnecessary fear, causing depression and creating a lack of motivation. Cahill et al (2006: 321) found that the main reasons reported by 300 Irish GPs for non-disclosure of dementia were: (i) difficulty in differentiating normal ageing from symptoms of dementia, (ii) lack of confidence and (iii) concerns about the impact of the diagnosis on the patient. It is evident therefore from the literature that many variables and factors are at play when considering the debate around disclosure.

A discussion on disclosure must also address the idea that people might not want to know their diagnosis and might not want to receive information about what is likely to happen to them in the future. Keating et al (2005: 1039) state that people should be treated as individuals, rather than adopting a policy of full automatic disclosure. Rice and Warner (1994: 470) on the other hand advocate for the patients' right to know about their condition: "our view is that people with mild dementia should be given enough information for them to understand the diagnosis and prognosis. Carers should not be given information that cannot also be imparted to the patients". They argue that in cases where the person's capacity to comprehend or cope with a diagnosis is under question, disclosure should be patient-led and carried out over a series of appointments. Their research concluded that at the moment there is no standard practice in imparting a diagnosis and/or prognosis of dementia.

The issue of standardised practices around disclosure is an important one. Vernooij-Dassen et al (2005: 379-382) found, in their study examining recognition and diagnosis of dementia across eight European countries[lvii], that Portugal and Ireland were the only two not to have developed guidelines for practitioners for early recognition of dementia and methods on how to diagnose and treat dementia at either a national or regional level. These authors (2005: 382-383) also found that health professionals believed that there was little to offer those with dementia and this subsequently led to a reluctance to diagnose. This was combined with pessimism about prognosis, "which in turn enhanced therapeutic nihilism in early stages of dementia". These authors identified a number of key issues in relation to timely diagnosis of dementia, namely: exploring and addressing the role of stigma perceived by physicians: paying attention to the symptoms of early-stage dementia; adopting a stepwise diagnostic process; promoting multi-disciplinary collaboration in making diagnosis and in early intervention; organising early interventions for carers, focusing on their individual needs, using instruments to measure caregiver competence; and developing early psychosocial intervention support programmes.

7.3.2 Disclosing in the early stages

A significance element of disclosing a diagnosis is that it is the first step in the implementation and engagement of effective coping strategies for living with and managing the illness (Wilkinson and Milnes, 2003: 303). Some argue that the issue of disclosure is different for those in the early stages compared to those in the latter stages. This debate centres on varying levels of awareness across the course of the illness. Pinner (2000: 516) argues that people in the latter stages of dementia have less awareness and therefore telling them would do no harm: "in the early stages of dementia, while the individual is still competent, it can be argued that a patient needs to know the diagnosis to enable choice, autonomy and future planning. In the late stages of disease the truth will neither benefit nor harm and

[lvii] The eight countries in the study were Belgium, France, the Netherlands, Ireland, Italy, Portugal, Spain and the UK.

disclosure is merely futile". Rice and Warner's (1994: 467) survey of Old-Age Psychiatrists' practices in disclosing a diagnosis of dementia found that while carers were almost always told, patients with severe dementia were almost never told. There was a tendency to disclose to those with a moderate dementia, while results were variable for people with mild dementia.

The benefits of early diagnosis are also described as the gateway to care (Alzheimer's Society of Ireland, 2007) and the earlier the diagnosis the sooner the person can, in principle, be connected to health and social care services. Early diagnosis can reduce morbidity and depression, reduce carer stress, reduce the need for crisis intervention and delay or prevent institutionalisation (Alzheimer Scotland – Action on Dementia, 2000). Alzheimer Scotland (2000) also states that medical and psychosocial interventions can prolong the period of time during which people living with dementia and their carers continue to enjoy their normal life patterns. Early diagnosis can reduce the extent of crisis management that the person living with dementia and those around them will have to undergo (O'Shea, 2000).

The preferences of older people on disclosure have also undergone scrutiny. A recent study carried out in Galway's Regional University Hospital (Keating et al, 2005: 1038)[lviii], found that 84% (N= 207) of older patients interviewed wanted to be told if they had a diagnosis of cancer or dementia. A study by Maguire et al (1996: 529-530) looked at people's attitudes towards disclosing a dementia diagnosis to a family member. A large majority, 83% (N=100), stated that their family member who had dementia should not be told, as it would upset or depress them. Interestingly, 71% of respondents stated that they

[lviii] The proportion of patients who would like to be told did not differ between the 'young old' and 'older old', with younger respondents registering an 86% preference of being informed. Of the 174 people who wished to be told, 140 (80.1%) wanted full details of their condition. The majority of patients wanted to hear their diagnosis without anyone else present (100 patients), while 70 patients wanted a family member to be present. Interestingly, despite the widespread practice of using people's families or carers as proxies when considering any discussion of disclosing a diagnosis only a small proportion (2%) wanted a family member to inform them of their diagnosis, with everyone else in the sample preferring a health professional to tell them.

themselves would like to learn of their own diagnosis if they developed a dementia. The authors state that "this inconsistency may reflect a general difference in the perception of the disease, a paternalistic desire by family members to protect patients of the harsh reality of their condition, or a reluctance of relatives to deal with the patient's knowledge and possible grief".

7.3.3 Findings on disclosure

Results from this thesis show how respondents' experiences of a dementia disclosure varied. The vast majority (N=14) were referred to an Outpatient Clinic so a definite diagnosis could be made, where they had low MMSE scores and were displaying early signs of significant memory impairment. As a result they received the diagnosis from a Consultant Geriatrician or from a member of their medical team. One respondent (Mrs Buckley) was diagnosed by an Old-Age Psychiatrist and another (Mr Barry) was diagnosed at a National Memory Clinic, while Mrs Doherty received a diagnosis from her GP. Only six respondents had been told they had dementia (Mrs Beattie, Mr Barry, Mrs Buckley, Mr Watts, Mr Murphy and Mr Doyle). All other respondents had been told they had a deteriorating memory impairment.

In asking a question during interviews about how a diagnosis was made what became evident was that five respondents (Mr Burns, Mr Murphy, Mr Moore, Mr Callaghan and Mrs Martin) presented to doctors with other illnesses or physical disabilities, although there were evident signs of dementia. In other words diagnosis was sometimes made when respondents went to their doctor for other medical issues, mentioning their memory failing during the consultation:

> *"No, doctors were coming in (the respondent was in hospital to convalesce from a lung-related illness) and I just said to him look there's something wrong with my head, like there's things I can't remember and all this sort of thing and he said OK I'll get another doctor. And that's the start of it, I got, I got*

> *scanned and all that sort of thing and they said it was the onset of it. You know. I've often, well I didn't often read but they were talking about it or it was in the paper where you get tablets for it you know, but it's only good for a year. Did you ever hear of that?"* **(030, Mr Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

This quote also shows the extent of Mr Murphy's insight and awareness of his diagnosis.

A policy expert interviewed for this thesis also highlighted the lack of referral for cognitive/memory disability and dementia, with a much stronger focus on other physical diseases:

> *"I was speaking with the Consultant Geriatrician recently and she's frustrated because she said she's getting people admitted into the service with let's say a diagnosis of a cardiac, a heart failure right, but she said when I look at these people, what these people really are is, is people with significant behavioural symptoms of dementia but they have been admitted into my service under the guise of heart failure* **(Care Group Coordinator for Services for Older People HSE, L41, p10/11)**

7.3.4 Responses to diagnosis

In most cases, respondents could not recall the exact time they were told their diagnosis of either dementia or memory impairment. As a result, although the interview guides included questions about diagnosis, the respondents spoke more about their emotional responses to having dementia, rather than the circumstances in which they had been told.

For some it was a shock:

> *"I actually got a shock when I, I actually can't remember but I know it upset me, course naturally. I didn't think that, I really didn't think that I was like that you know and emm and other, at the time,*

when was it anyway. I don't know when it was, I can't remember when it was" **(018, Mrs Buckley, female, 79 years, Alzheimer's disease, lives with spouse)**

The emotional response was equally difficult for many care-partners:

"When you're told something like that you don't take it in. You really don't take it in, it doesn't sink in, you know and it was a couple of days after that it hit me, you know. Of course I got so depressed I was three days I wouldn't come down, I couldn't I couldn't talk to no-one, I just went, my mind went totally blank. I couldn't think of nothing I couldn't even think of my daughter's phone number" **(C034, Mrs Doyle, female care-partner, spouse)**

Mrs Doyle talked about how distressing the experience was:

"Care-partner: Dr. ------- just brought us into the office and explained it, you know and he said to us like you know, it's not a death sentence it's a thing you can live with and that you know there's great painters and great what do you call it and kind of, you're not taking that in when you're hearing it you know, you know. It was just when he brought me down to see to talk to the psychiatrist for a few minutes I just kind of broke down, I filled up and broke down, it hit me then when I came outside you know. Cause I just, it's so unfair like, to think we've been together so long and just getting married then and only having three years of, do you know what I mean, it did it hit me with a bang" **(C034, Mrs Doyle, female care-partner, spouse)**

Mrs Doyle's experience also shows how her meeting with the psychiatrist was more productive in her taking in the diagnosis, in comparison to her discussion with the geriatrician. Although the geriatrician was trying to conceptualise dementia within a positive framework, the care-partner tells us she could not take it all in.

In another case where Mr Murphy was given his diagnosis, the doctor covered three main topics – enduring power of attorney, undergoing a driving assessment and taking anti-dementia medications. The respondent had a very clear memory of this experience. He felt that the doctor focused on issues that were unrelated to his prognosis or his emotional and psychological needs and he was very upset about the whole experience:

> *"I don't think, well, I don't think, well what I said to you first was you know, you know get the power of whatever and get onto the driver, them things and all, he (the doctor) was on about them things and then other things and all sorts of things and then when I asked him, 'well right what's it going to be for me'? And I actually said to Maggie (his wife) you know 'he sounds like a fella who's touting for you know the, ah feck.... the insurance and all that sort of thing, or the insurance people are telling him anybody comes in with that tell them, you know"*
> **(030, Mr Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

Mr Murphy did not have a follow-up appointment at the hospital after he was diagnosed. He was due to attend the clinic, as normal, six months' after he was diagnosed. Therefore, the only opportunity he had to ask questions and receive information about his illness was during the appointment where he was told he had Alzheimer's disease. As a result he was very negative about the experience when talking to me. His experience also supports the idea that a clinical approach to disclosure does not meet the person's needs.

For others the disclosure allayed fears of 'going mad'. People living with dementia can realise that something is wrong but can be unaware of what is happening to them (Pinner and Bouman, 2003: 336). In Mrs Beattie case she was glad to know her diagnosis; she stated that having Alzheimer's disease was preferable to having a brain tumour:

> *"Interviewer: Were you glad to know what was wrong? Respondent: Oh I was glad that it wasn't, in the sense of having a brain scan that it wasn't a tumour, like cancer or something"* **(004, Mrs Beattie, female, 67 years, Alzheimer's disease, lives alone)**

> *"Interviewer: Are you glad you know that it's Alzheimer's disease? Respondent: Well I'm glad I know because I didn't even know I was, I was forgetting things. And no it was a shock. I got used to it"* **(018, Mrs Beattie, female, 79 years, Alzheimer's disease, lives with spouse)**

Findings show that relief can be associated with receiving a diagnosis as it provides an explanation and the person can begin to address the issue. People living with dementia can also be aware of changes in their memory and practical difficulties that are arising regardless of whether or not they have been told their diagnosis. In conjunction with positive outcomes of receiving a diagnosis negative responses were also felt in:

> *"Interviewer: And having received a diagnosis of dementia has it affected how you see yourself? Your confidence or your self-esteem at all? Respondent: Oh yes, I do notice Emer I'd rather be, very much prefer to be on my own. And yes, that is the truth now"* **(004, female, 67 years, Alzheimer's disease, lives alone)**

Mrs Beattie became very withdrawn after her diagnosis; she lost a lot of confidence. Further discussions with her revealed that she had a history of anxiety and depression. On the one hand she experienced relief in knowing the cause of her memory changes. This relief had a positive impact on her understanding and acceptance but she also experienced negative outcomes where she became depressed and withdrawn. This is a good example of how continuous support could have helped the person adjust to a diagnosis, particularly in the light of Mrs Beattie's history of depression.

Mr Moore provides another example of negative outcomes, particularly relating to confidence:

> *"Interviewer: And how would you rate your confidence at the moment? Respondent: I'm not sure of anything. Interviewer: You're not sure of anything? Respondent: No. Interviewer: Has that changed, you used to be more confident? Respondent: Oh God yes. Interviewer: And is that because of the mobility or because of the memory, that you're not as confident as you were? Respondent: Oh memory"* **(036, Mr Moore, male, 93 years, mixed Alzheimer's disease and vascular dementia, lives alone)**

7.3.5 Prognosis, feedback and information

A key theme identified from the data around the practice of disclosure was the dissemination of information afterwards. Percival and Hanson (2005: 196) found that people who were experiencing other types of disability in older age also identified the need for "strategies that provide accessible and wide-ranging information to the maximum number of people, in a pro-active rather than reactive way". Findings from this thesis support the need for pro-active strategies in the provision of information.

Many respondents and their care-partners had questions about their prognosis, what to expect in the future and about what was happening to them now. Connected to this was feedback from medical professionals after assessment. In nearly all cases respondents did not see the hospital consultant or another member of their team for a further six months or even a year after diagnosis. There was no practice of being recalled for a feedback session following diagnosis:

> *"I suppose feedback is the biggest thing in my mind. I think we should be told more about the progression about the illness and certain things to look for and*

things like that" **(C020, Mrs Watts, female care-partner, spouse)**

Mrs Curran was never given the opportunity to discuss her situation fully with a doctor:

"No I never discussed it with a doctor, you know" **(010, Mrs Curran, female, 74 years, Alzheimer's disease, lives with spouse)**

Many respondents wanted to know what was happening to them and about what to expect in the future and the failure to meet this basic need emerged as one of the most glaring shortcomings in the current systems of care for people with early-stage dementia in Ireland.

7.3.6 Non-disclosure of a diagnosis

It has already been stated that not everyone was told they had dementia; some people were told they had a memory problem. One reason for this identified from the data was a desire by families to protect the person. In Mrs Curran's case, following the Outpatient appointment the onus was on the family to tell her as the doctor did not mention her diagnosis to her. Rather than risk upsetting his wife, Mr Curran chose not to talk about the dementia although he knew she was aware that she had a memory problem:

"Interviewer: Did they [medical staff] ask you whether you wanted to tell her or not (the diagnosis)? Care-partner: No, they didn't say anything about that really. Interviewer: So they didn't give you the opportunity... Care-partner: No, they didn't maybe they thought that I would mention it but eh, she kind of when the word Alzheimer's is mentioned she gets a little bit upset about it. I don't know, she thinks 'thank God I haven't got that, like you know'. Interviewer: And do you find it hard not telling her or... Care-partner: Well no, we put it down her problem is memory loss, which maybe is another name for Alzheimer's plus maybe another few things.

So she's happy enough to live with that" **(C010, Mr Curran, male care-partner, spouse)**

Another respondent, Fr Hanrahan was aware he was on anti-dementia medication, but he either had not been told or could not recall why:

"Interviewer: And did the doctors talk to you about why you were going on the Aricept or anything like that? Respondent: Well I had some other tests and so on, I went to various specialists and so on. I wasn't really aware of it, but they didn't look on it as anything very serious. But then they asked me and put me on that, what do you call it? Interviewer: Aricept. And did the doctor give you any reason for why? Respondent: No, no" **(033, Fr Hanrahan, male, 70 years, Alzheimer's disease, lives in religious community)**

Receiving a diagnosis was also dependent on GPs identifying the early signs of dementia. In one case Mr Burke's GP passed off the early signs as normal ageing:

"Yes, actually I had mentioned to his GP about a year and a half ago, because I thought, he said to me 'does he do anything dangerous like leaving the cooker on'. But I said 'no he never touches the cooker, he never touches the cooker'. So that kind of made me, but it, since I'd say the past year I noticed a couple of things, he'd misplace and forget about them, it happened even with the driving license, a new driving license that had arrived ... Interviewer: And your GP didn't have any other concerns just about leaving the cooker on when you mentioned it to him? Care-partner: No he didn't because he said to me sure I forget things myself like" **(C023, Mrs Burke, female care-partner, spouse)**

Mr Burke was later diagnosed with Alzheimer's disease although the symptoms of the illness were evident a year and a half before diagnosis.

Another issue for some families was accessing specialist services to receive a diagnosis. Although all respondents were receiving specialist old age care from a hospital department, a policy expert acknowledged the difficulties for public patients in accessing specialists to receive appropriate diagnosis and assessment:

> *"I would also say there may still be problems for public patients about actually accessing diagnostic, consultant services, although I don't actually know what the waiting list is. Part of the problem is because some GPs are reluctant to refer older patients to specialist services but it also may result from lack of availability in some areas".* **(Former Director of Services for Older People, HSE East Coast Area, L42, p4)**

7.3.7 Section summary

Whilst all of the men and women included in this study had dementia, only a minority (N=6) had been explicitly and clearly told at the time of diagnosis that they had dementia. Others were told they had a memory loss problem. The debate around disclosure is still ongoing. Some argue that people should automatically be told their diagnosis, while others feel that it should be led by patient preferences or the stage of dementia the person is at. Reasons why respondents were not given an early diagnosis in this research include desire on the part of families to protect the person, or the failure of a GP to identify and correctly interpret the early signs. There is no standardised practice for doctors around disclosing a diagnosis and one doctor, from the respondent's point of view, was overly concerned with legal and financial matters which affected his response to the diagnosis. We do not have national standard guidelines on the disclosure of dementia diagnosis, which results in a very subjective system, depending largely on families' and specialists' preferences and beliefs. A serious consequence of this is that some people are able to seek and

access further services because they have received an appropriate and extensive diagnosis while others are not referred at all due to the lack of a correct and timely diagnosis.

The following section addresses psychosocial interventions after diagnosis, paying particular attention to the issue of rehabilitation.

7.4 Psychosocial Interventions and Rehabilitation

Psychosocial interventions for people living with dementia are often ignored within a medical framework of intervention (Clare and Woods, 2001: 193). Even though in recent years there has been greater recognition of the number of psychosocial interventions that benefit those with dementia, they are often not offered to people immediately after diagnosis, which was the case for many respondents in this study. Findings emerging from this study show that those respondents who had received psychosocial interventions reported positive outcomes. Others expressed interest in receiving such services but this was difficult due to the lack of resources available to provide these services and a general lack of referral to the services that existed.

Findings from this thesis have shown that people experience reduced confidence with the onset of dementia (see Chapter Five, section 5.3.2). Fundamental elements of psychosocial or therapeutic interventions are that they should "enhance quality of life, arrest mental decline and generate and maintain self-esteem...to create immediate pleasure, re-establish dignity, provide meaningful tasks, restore roles and enable friendships" (Marshall and Hutchinson, 2001: 488). This should be the ethos guiding the development of all dementia-specific interventions.

Recently there has been an emergence of literature and services targeting the rehabilitation of people living with dementia. Rehabilitation means "to make able again" (Wilson, 1997: 487). The World Health Organisation (1997) states that "rehabilitation implies

the restoration of patients to the highest level of physical, psychological and social adaptation attainable, it includes all measures aimed at reducing the impact of disabling and handicapping conditions and at enabling disabled people to achieve optimum social integration" (Wilson, 1997: 487). Graham et al (2001: 429) found that some learning is possible in the early stages of dementia, specifically around word-finding difficulties. Psychosocial interventions can also impart useful learning techniques to support and improve memory, thus enhancing everyday living.

Maintenance and coping programmes for people living with dementia and their families exist in other countries, for example self-maintenance therapy (Romero and Wenz, 2001) and training in validation therapy (Feil, 2002) is also provided elsewhere (Alzheimer's Australia). However, similar programmes do not exist in Ireland, serving as a further example of the difference between the Irish system of health and social care and countries where interventions are more widely available. As was shown in an earlier section, three respondents attended a Day-hospital where they received other auxiliary therapies. This helped them to acquire coping and memory techniques. Despite the positive feedback from receiving such interventions, in most cases respondents did not receive any dementia-specific follow-up after diagnosis.

7.4.1 Interventions available to respondents

As mentioned earlier (see Table 7.2), two respondents in this study had contacted the ASI and only three had attended the Day-hospital. Two respondents were attending a Day Centre and one respondent had been assessed by a social worker.

Referral to a Day-hospital was through the hospital's Outpatients Clinic. A Day-hospital offered programmes tailored to the individual, dependent on their needs. During attendance at the Day-hospital, people living with dementia generally undergo a thorough memory and cognitive assessment by an Occupational Therapist and they are given strategies for improving memory in day-to-day living,

including practical tips and memory exercises. As all respondents in this study were recruited from the same hospital, it is interesting to note the low numbers that were referred to the Day-hospital. Referrals to a Social Worker were made if someone was identified at the weekly multi-disciplinary team meeting as having an inadequate social network or they had income/medical card problems, if a high level of caregiver stress was detected, or there were behavioural changes associated with the illness. Automatic referral to a social worker after diagnosis did not occur.

7.4.2 Day Centres

One of the main responses to the psychosocial care needs of older people is found in the provision of Day Centres. Day Centres can offer respite for family carers and there has been some evidence to suggest that it can reduce the likelihood entry into long-term care (Andrew et al, 2000). However, in a study looking at the attendance of people living with dementia at Day Centres, Måvall and Malmberg (2007: 39) found that over half of their sample of people living with dementia stopped attending a day centre within 12 months, largely due to challenging behaviours, with depression the most significant predictor of an early end to participation in day care.

Zarit, Gaugler and Jarrott (1999: 169) report that people living with dementia usually attend adult Day Centres in the later stages of their illness and the decision to attend is usually made by caregivers, possibly reflecting their needs rather than the needs of the person living with dementia. This does not negate the benefits people living with dementia can derive from attending these centres.

As was shown earlier, at the time of interview only two respondents regularly attended a Day Centre. Two others had at one time attended a Day Centre but had stopped going. The majority of respondents interviewed for this thesis did not see Day Centres as an option for them. Data shows that group activities were not attractive options to everyone, due to personal preference and/or personality type:

> *"All the years now, she wouldn't join ladies clubs or anything like that she wouldn't go into one of them...no it wouldn't suit her, once she had me she didn't care who she had"* **(C018, Mr Curran, male care–partner, spouse)**

However, non-attendance at Day Centres should not be assumed, even in cases where people had no history of joining clubs or engaging in group activities:

> *"I'm not a joiner, but that's not to say I wouldn't go"* **(030, Mr Murphy, male, 70 years, person living with dementia, lives with spouse, Alzheimer's disease)**

Those who had attended a centre reported some positive and some negative outcomes. The following section examines positive outcomes from attending a Day Centre and also considers some of the reasons why attending a Day Centre was not considered by the majority of respondents.

Positive experience of Day Centre

Data show how the context in which respondents were referred to and attended the Day Centre affected their views:

> *"We're in the, the two of us go now to the club there in eh, is it C------, W---------, you know and they do a few things, play bingo and things like that. I'm not into anything like that you know but we're only new in that"* **(041, Mrs Martin, female, 77 years, Alzheimer's disease, lives with spouse)**

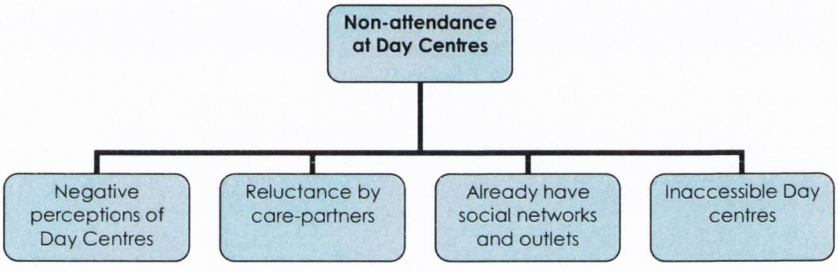
The centre which Mrs Martin was attending was specifically for people living with dementia but she did not perceive it as such and felt that it was beneficial to her husband who was cognitively well. Mrs Martin also referred to the Centre as "a club". This suggests she was not aware of the specific nature of the dementia Day centre she was attending, and may also have reflected a positive perception of the centre as a relaxed, comfortable and non-stigmatising environment:

> *"I said to him that it's to keep you young... Well now we're starting to go to the club down there and for,*

like for us for to keep you floating you know" **(041, Mrs Martin, female, 77 years, Alzheimer's disease, lives with spouse)**

Figure 7.1 summarises the main reasons why the majority of respondent did not attend a Day Centre.

Figure 7.1: Reasons for not attending Day Centres



(i) Negative perceptions of Day Centres

In general attitudes to Day Centres tended to be negative rather than positive. Many perceived them as places where nothing happened and thought that attending a centre would reflect their loss of independence:

"Oh no I'd hate that, oh I'd hate that, I'd hate that. To listen to all the moans, oh no, enough moans of my own" **(029, Mrs Lynch, female, 87 years, lives alone, Alzheimer's disease)**

"I did go down to the Day Centre and I nearly went out of my mind...oh my God...(laughs) I don't know I just couldn't, I said I'll go home and be independent (laughs)" **(035, Mrs Doherty, female, 76 years, vascular dementia, lives alone)**

The set-up and organisation of Day Centres were also perceived as negative. The absence of meaningful activities to engage in whilst at the Day Centre was a source of concern for some:

"Well I went down and the chairs were along there (indicates chairs in a line up against the wall) and we

> *sat in them chairs for I don't know, hours, doing nothing. And then I didn't go back. And she rang and said 'what, are you not coming?' And I said 'I can sit in my chair at home'. You know, I said to her 'we weren't doing anything' you know"* **(035, Mrs Doherty, female, 76 years, vascular dementia, lives alone)**

The lack of meaningful activity reflects a culture within many day centres which fail to focus on abilities. It highlights the role of the day centre as largely a respite for care-givers.

Mrs Doherty was then asked:

> *"If the Day Centre did more activities would you like to go to something like that?"*

And she responded:

> *"No I don't know, if I could learn at this stage in my life, new things I don't think I'll go back...well I tell you, what it was, old people there and they weren't talking to each other, they were just sitting in chairs...staring into space and I said, I said I can go home and do that. I was in there for three days sitting in a chair and nothing happening, of course you're fed up, well fed up (laughs) well fed-up"* **(035, Mrs Doherty, female, 76 years, vascular dementia, lives alone)**

Mr Doyle disliked the association of Day Centres/retirement groups with older age:

> *"I wouldn't go near the bloody retirement centre that's the truth...look I might be seventy something but I don't want to meet a shower of old cronies, auld fellas like that, I don't and that's the truth. I'm quite happy now with Maureen, she's the oldest one I'm with (laughs)...I think you want to be, they wouldn't be my type. They wouldn't be my thing anyway other than say the least of it. Though I have*

no opinion on them...no I'm not interested in them"
(034, Mr Doyle, male, 76 years, Alzheimer's disease, lives with spouse)

This suggests that Mr Doyle did not want to be reminded of ageing or becoming old and had no interest in socialising with other older people unfamiliar to him at the Day Centre. It also links back to the loss of independence that many people associate with attending a day centre.

(ii) Reluctance by care-partners

Care-partners' motivations sometimes prevented respondents from attending a Day Centre. If they did not need respite themselves they often preferred the person to stay at home and be company for them, or they felt guilty about the person going to a centre. In all cases, where this reluctance was expressed, it was by a spouse care-partner whereas adult children tended not to have as many concerns about accessing these services:

"Eh no he likes to be here... I wouldn't send him to a Day Centre it's not him you know" **(C039, Mrs Callaghan, female care-partner, spouse)**

It could be argued that care-partners' reluctance to see their loved one attend a Day Centre or a dementia-specific group had its origins in stigma around dementia and the stigma of using specific services for older people. In an earlier chapter we saw how people often waited until a critical incident before seeking interventions. Day centres were not seen to respond to critical incidences and were primarily perceived as a respite for caregivers rather than as something that the person living with dementia might enjoy and benefit from independently of their carer's needs. Many care partners had never availed of social care services in the past and to do so now, they felt, would feel like 'failing' the person living with dementia in some respects.

In one case a care-partner decided that it would be better if he attended the Day Centre with his wife rather than her attending the

centre alone as he suggested she was reluctant to things without him:

> *"Well you see I don't, I don't know what, would she avail of them. She's not, she'd rather be comfortable at home with me than going out. Now I'm hoping like that emm going down to the club on the Wednesday that ehh she herself, like I could have them coming up and collecting her but she wants me there"* **(C041, Mr Martin, female care-partner, spouse)**

(iii) Already have a social network/outlet

Day Centres are often promoted on the basis that they provide a social outlet for older people, generating a valuable social network. However, some respondents did not perceive this as a concern for them as they had a sufficient number of contacts:

> *"No, I'm not into that to be quite honest with you...because I have enough of friends"* **(038, Mrs Gannon, female, 62 years, Alzheimer's disease, lives with spouse and daughter)**

When Mrs Burns, a care-partner, was asked about the possibility of her husband going to a Day Centre, she responded:

> *"I'd be reluctant to do it now. You see he goes swimming twice a week and he goes walking and you know, so long as he can do that he's in contact with people and one day a week he goes to the canteen in the ESB (previous employer) for his dinner and like he'll meet people down there, that's really the extent of his social life really"* **(C017, Mrs Burns, female care-partner, spouse)**

Other respondents expressed no interest in attending a Day Centre, as they were sufficiently happy with their current social circumstances:

> *"Not particularly, I'm, I'm happy enough, like we have good television here and we have another one*

> *upstairs (laughs) like if I want to watch football I can go upstairs and watch it, my wife can watch something else here"* **(020, Mr Watts, male, 70 years, Alzheimer's disease, lives with spouse)**

Mr Watts did not perceive the Day Centre as a way to improve his quality of life. Like many others in the sample, he was content with continuing on with the activities he formally enjoyed.

(v) Inaccessible Day Centres

Day Centres were not always accessible for people in the sample. The interview data indicated that some centres were physically inaccessible due to transport problem or not accessed due to the lack of awareness about services. Some people had never been referred to the service and no-one had ever mentioned it to them:

> *"Yeah if it now this is, might say it wrong, but if somebody would bring me up you know, because everything is up at the top of the town, there's nothing down here you know, there are places up there where, for the old and all that sort of thing"* **(030, Mr Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

7.4.3 Support groups/counselling

People living with dementia and care-partners were asked about the extent to which they availed of support groups and/or counselling services. Interestingly, most respondents did not perceive a benefit from talking about their dementia or memory and cognitive change in a formal support group or counselling setting. Respondents in this study are from a generation where counselling was not commonly undertaken:

> *"If I was in a crowd, not a crowd of four or five or six or seven you know and you hear them moaning and all this sort of thing I couldn't stand that. And that would annoy me"* **(030, Mr Murphy, male, 70 years, Alzheimer's disease, lives with spouse)**

However, support groups and counselling were not dismissed as of no value by all:

> *"Well not at this stage but possibly later you know"* **(C023, Mrs Burke, female care-partner, spouse)**

Some respondents did appreciate the benefits of others speaking to them about their experiences, as this gave them the opportunity to open up about their own experiences. How interventions are framed can encourage or discourage participation:

> *"Interviewer: When you got your diagnosis, would advice and support have been useful to you? Respondent: Ah yes. Interviewer: What kind? Respondent: Like if it was, like a little meeting that you could go to, people have, that have this struggle. To have a chat like you know...."* **(004, Mrs Beattie, female, 67 years, Alzheimer's disease, lives alone)**

7.4.4 Section summary

The paucity of psychosocial interventions for people living with dementia in Ireland was reflected in respondents' low use of this type of services. None of the respondents in this study had had a full bio-psychosocial assessment. None had been consulted to develop an appropriate care plan. Most were receiving few interventions: two were attending a Day Centre and three had attended a Day-hospital.

One of the main interventions for people living with dementia and their families after the onset of dementia is attendance at Day Centres. However, these were not seen by the majority of respondents as a positive or beneficial response to their situations. Findings showed how counselling was not offered to people through the public health system and it was not desired by the majority of respondents. A reason for this could be a lack of knowledge about what this service involves.

7.6 Chapter Summary

This chapter reiterates some of the themes emerging from data analysed in preceding chapters, namely the stigma of dementia, the heavy reliance by the Irish State on family members to provide home care, the way in which Irish community services tended to be based on medical as opposed to psychosocial needs and how respondents living with dementia and their families were treated in an already over-stretched system and one which was not particularly supportive of their day-to-day needs. Some of the data provide rich and compelling evidence of the benefits derived from certain service interventions in the community such as OT and PHN visits, yet for the majority of people in this sample such services were not available. The PHN service often did not meet the needs of respondents because of its medical focus, yet contact between care-partners/respondents and the local PHN was often deemed extremely valuable.

Best practice in dementia care recognises the need for an early diagnosis, in order for medical treatments to be introduced and for health, social and legal services to be explored, at a time when they are likely to be most effective. One of the most significant and alarming findings in this chapter was the lack of further information to respondents immediately following the diagnosis. The people in this sample had many questions about their illness and about what to expect in the future. Many of their thoughts about the future were centred around fear of becoming dependent and a burden on others or having to go into long-term care. Where information was given to respondents at the time of diagnosis it was not seen as relevant or appropriate. There were of course a small number of respondents who preferred not to know about their dementia but by and large this type of information would have been very helpful to most of these individuals and families and was not available to them.

A key goal of early intervention services is that of challenging stigma in society. The data here show that in most cases, the doctors

responsible for diagnosing respondents tended to avoid using words such as Alzheimer's disease and dementia when conveying the news of the illness to the person and instead used less threatening softer words. It could be argued that by avoiding spelling out a diagnosis, these doctors were entering into a conspiracy of silence and further contributing to the stigma of dementia in our society. The disclosure of a life changing illness like dementia should be a process rather than a once off event and one that incorporates support at a practical, emotional, medical and social level. This was not always the reality for the people in this sample. After diagnosis, none of the men and women in this sample had had appointments at the Outpatient clinic to further discuss their concerns and issues. Findings show that the clinical setting was not always conducive to receiving and taking in a diagnosis in a manner that offered reassurance. At the time of diagnosis, many were shocked and distressed and therefore would not have been in a position to comprehend and absorb advice and/or process information.

An interesting finding from this chapter relates to stigma and diagnosis. Mrs Burns, who initially was initially embarrassed by her husband's loss of memory and communication difficulties, however once a diagnosis of dementia was made, she no longer felt embarrassed and expected others to react and interact with her husband in the same way she now did, which was with complete acceptance. This is interesting because in this case the 'label' of dementia challenged stigma instead of creating it.

Where techniques for coping were offered they worked well but only three respondents had been offered this kind of individually tailored training through a Day-hospital. In a community care system that depends largely on self-referral, respondents' contact with key service providers affected their referral to other services. In the absence of standardised practices, referral is very subjective and dependent on the knowledge and connections of the referral body or the referring professional. Referrals tended to have a snowball effect: when one service was being accessed there was greater

opportunity to receive a referral to another intervention/service. Community-based services were largely health-focused and medically-based, with few social or psychosocial supports. For example, the roles of Speech and Language Therapists, Social Workers, Counsellors and Occupational Therapists were marginal. The ASI is making strides in developing psychosocial services for people living with dementia through their social club model, advocacy programme, social inclusion programme and their support groups, but these are not yet widely available and there was little evidence of respondents or their care-partners accessing any of these services.

The system of health and social care that the respondents lived within was focused towards medical and physical need. I feel this created a culture where responses to dementia other than medical interventions were not known or not valued. The rich data from respondent interviews shows us some of the dilemmas these men and women experienced, some wishing to avail of services that were inaccessible (such as PHN services), others resisting services that were available (Day Centres) due to perceived stigma, or because of the way in which the service was delivered. A key finding was that nobody in the sample had a key case-worker to support them throughout the early stages of the illness trajectory. Service provision could be characterised as 'hit and miss' and several of these families learned about formal services through their friends or through informal networks. Several would have valued opportunities for more support.

Chapters Five and Six showed how respondents attributed meaning to changes in their cognition and memory, normalising the process or finding reasons for what was happening. These findings can be applied also to the development of services for people with early-stage dementia. Services and interventions will only be successful if they have meaning within the lives of service recipients. For example, Mrs Moore went to the Alzheimer's day centre with her husband and the context in which she went was as a social outing with her spouse. It was a successful intervention for her as a result, unlike Mrs Doherty

who saw no meaning in her attendance at a local day centre. Indeed there were no meaningful activities offered to her there.

The role of care-partners was also central to respondents' experiences of formal services. For example, findings show how they often gathered and collected valuable information on dementia and on the services that were available to respondents and what their entitlements were. In some cases care-partners also acted as the co-ordinator of the formal services respondents were receiving; in this way they were assisting in the maintenance of independence. Findings also show that the current system of care's dependence on care-partners is tenuous; particularly the future role of children who care for a parent. Therefore, in any further development of the formal care system, the role of the informal carer needs to be taken into account.

Chapter Eight, sections 8.5.1.1 and 8.8 draw heavily on findings presented in this chapter in relation to respondents directing service development and in relation to people with dementia as a collective (applying the citizenship model).

CHAPTER EIGHT: POLICY IMPLICATIONS

8.1 Introduction

This chapter draws on data collected from interviews with six policy experts reporting what they perceived to be the key policy issues and priorities in dementia care in Ireland. Chapter Three has already outlined the policy context of the thesis and this chapter will refer back to information presented there. This chapter also further summarises findings presented in the three preceding chapters, presenting widely shared experiences of dementia among respondents and examining the policy implications of this. In this way it addresses the research question pertaining to 'the policy implications of an investigation into the lived experience of dementia'.

8.2 Expert Views on Current Policy Context

In general, the policy experts interviewed in this research expressed similar opinions and attitudes (as reflected in government reports e.g. The Years Ahead Report, 1988) about the importance of home based services for older people with a dementia. A key issue for them was the need for an appropriate and realistic allocation of resources to community services to help people with dementia live at home for as long as possible. One expert argued that because there was so much emphasis given to long term care services and their finance in the 90's in Ireland (with the advent of the Health (Nursing Home) Act, 1990), community services were effectively squeezed out:

> *"Any available funding in the 1990s went into nursing homes and subventions. Which meant that, it wasn't really a time that much thought was put into the actual home resource allocation issue for older people ... But there was essentially no community care policy; well there was a community care policy but it wasn't being*

> *implemented""* **(Author of An Action Plan for Dementia[lix] and Director of the Irish Centre for Social Gerontology, L46, P1)**

The policy experts interviewed for this thesis unanimously called for a new national policy for older people and for the current strategy, 'the Years Ahead Report' (1988), to be updated. It was seen as timely to do this in light of the redevelopment of the health service from localised health boards to a national Health Service Executive (HSE):

> *"Even at present there is a view certainly that we should be moving towards a national policy for older people's services... I think lots of areas are still working [on the basis] of the local policies"* **(Care Group Coordinator for Services for Older people, HSE L36, P2)**

> *"I do think that we need a new strategy on ageing and older people that covers all areas of older people's lives. We also need a replacement for The Years Ahead, the 1988 health and social care policy for older people. I personally think, that the strategy and a revised health and social care policy everybody can stand behind, should be developed up front, in consultation with older people"* **(Former Director of the NCAOP, L17, P4)**

A key issue in this quote is the reference to user consultation. This gives the older person, in this context, influence which promotes empowerment, agency and citizenship. In the context of his comments, it is interesting to note that in the Programme for Government 2007-2012 a commitment has been made to develop a Positive Ageing Strategy in the lifetime of the current government.

Whilst as part of the re-configuration of the Health Board system into the Health Service Executive in 2005 an attempt was made to bring

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[lix] This is the leading dementia-specific report in Ireland, published by the National Council on Ageing and Older People in 1999.

about unified national policy development and practice implementation, the experts thought that this new service framework was still at a developmental stage:

> *"I mean traditionally what has happened is that each area, each old health board area had a policy... you had no joined up thinking really in relation to national policy"* **(Care Group Coordinator for Services for Older People HSE, L30, P2)**

This lack of co-ordination had, in their view, created an inequitable service, the type and extent of service provision being dependent on where you live and the regional allocation of resources to older people's services.

The lack of formal, rational planning in relation to service development and the belief that service initiatives often emerged in direct response to a crisis rather than being carefully planned and delivered was a view held by several of these experts:

> *"There's a tradition in this country of developing services incrementally, without really developing the proper foundations"* **(Former Director of Services for Older People, HSE East Coast Area, L26, P3)**

> *"Maybe I'm wrong about this, but I think we are pretty poor at planning generally speaking in this country...we're inclined to make policy decision[s] and planning decision[s] in response to crises. And we're not too given to determining and generating the information we require for policy and planning development in advance."* **(Former Director of the NCAOP, L41, P3)**

Overall, interviews with policy experts suggested a need to move away from an incremental approach to policy development and

towards a more rational plan or strategy for service development which would involve consultation with service users.

8.3 Dementia-specific Policy Development

In terms of developing dementia-specific policy, one of the experts interviewed stated that we need to stop reinventing the wheel and operationalise existing strategies and recommendations:

> *"We need to try and take elements of the report [the Years Ahead Report] really and concretise them, really make them, operationalise them really, that they can actually be rolled out. I suppose like any strategy it's more strategic and... the challenge now really is to put that into a workable document..."* **(Care Group Coordinator for Services for Older people, HSE L6, P10)**

The review of policy in Chapter Three showed that the key policy document on dementia, 'An Action Plan for Dementia' (1999), is now nearly ten years old. Only a small number of its recommendations were ever operationalised and these largely pertained to the further development of medical services in old-age psychiatry and geriatric medicine, and not to social services. This is indeed ironic since the Action Plan itself involved extensive community consultation and the report lobbied for a more social and holistic approach to be taken to dementia care in Ireland. This focus on medical provision in relation to dementia policy suggests an entrenched medically-focused culture of care in Ireland.

In discussion with these experts about dementia as an age-related illness, a view was held by some that this was not an area of priority for government official and bureaucrats:

> *"The HSE has not shown [a] great interest at a national level in dementia up till recently"* **(Former Director of Services for Older People, HSE East Coast Area, L40, P1)**

This policy expert was referring to the recent establishment of a national committee to look at dementia-specific services.

Finding from interviews with respondents and their care-partners show that in relation to service development and interventions an incremental approach existed. For example, a care management system did not exist for them; there were no care co-ordinators; respondents experienced few links between hospital and community services and few non-medical supports were provided to respondents. Services tended to be based on critical intervention rather than long-term strategy and underpinned by the medical model of care.

Marshall (1990: 10) states that much of dementia policy is unwritten but "what is certain is that all policies involve some basic beliefs and values about the nature of mental disability and about the place of elderly people in society". Policy experts in this study reiterated Marshall's belief. When asked what their thoughts were the reasons for a lack of dementia-specific policy development, they stated that the attitude and culture of a society often dictates the development of policy and practice:

> *"In a sense public awareness, public attitudes, public expectations and so on about dementia would still I think be on the low side"* (**Author of An Action Plan for Dementia and Director of the Irish Centre for Social Gerontology, L15, P3)**

As a result of such ageism, dementia-specific policy development has remained under-developed:

> *"It was very difficult during the '80s and '90s to have an impact on public policy particularly through research because the level of interest in older people's issues was relatively low... I think it was across not just the political structure but within society generally; older people were not seen as important; were not seen as a group that much needed to be done about"* **(Author of An**

Action Plan for Dementia and Director of the Irish Centre for Social Gerontology, L36, P1)

In the 1990s there was a shift in dementia care, leading to a greater focus on the person with dementia. A policy expert interviewed for this thesis (the CEO of the ASI) outlined some of the reasons for a renewed focus in Ireland on the person with dementia. One of these was an influence from outside of Ireland:

> *"From my point of view the biggest influence I've had is not within Ireland, it's been because I've got involved in the Alzheimer's Europe. And would have shared the insights of other people that were far ahead of what we were doing here, now that doesn't mean to say we're not catching up, we are, very fast, but initially when I started here there was nothing"* **(CEO of the Alzheimer's Society of Ireland, L35, P11)**

Other reasons for this change in focus put forward by the same policy expert were the development of the Dementia Services Information and Development Centre and the involvement and influence of a number of key Consultant Geriatricians and Old Age Psychiatrists.

> *"Some key consultants, I mean like ------ ---------, and in his own way ----- ------- and a number of others"* **(CEO of the Alzheimer's Society of Ireland L45, P11)**

This was reinforced by increased investment in the area of Old Age Psychiatry, as shown above:

> *"I suppose the Psychiatry of Old Age there was a greater investment, there was also a greater bank of knowledge about what was possible in terms of medical know how and response"* **(CEO of the Alzheimer's Society of Ireland L47, P11)**

This expert went on to reflect on the use of anti-dementia medications and how their introduction and widespread use have helped to change the focus:

> *"I suppose the anti-dementia drugs have helped somewhat in that they have, they have given some kind of hope"* **(CEO of the Alzheimer's Society of Ireland, L49, P11)**

He also spoke about the importance of rehabilitation in the context of dementia and of learning from other disability groups:

> *"That's a very important part of the refocusing of or the new focus if you like of wanting to respond to the needs of people with dementia themselves, rather than just looking at the needs of the carer and I suppose that comes about by, from our point of view and from my point of view, it would be looking at the disability rights movements... Other than cure we've had to look at therapeutic interventions"* **(CEO of the Alzheimer's Society of Ireland, L6, P2)**

8.4 Policy Experts' Policy Priorities

In 2007 the ASI, in their 'Dementia Manifesto', called for dementia to be made a national health priority. During interviews for this thesis each policy expert was asked their views on dementia-specific policy priorities in Ireland. It has already been shown that several called for a new or updated national strategy for older people. The following section outlines other service priorities the policy experts believed were in need of development.

8.4.1 Improved services

Overall there was consensus amongst the experts interviewed that professional services for older people across the HSE needed to be made more person-centred and improved. There was a perception that services were overstretched and should be more specific to older persons. One expert spoke quite eloquently about the fact that Public Health Nurses were expected to provide a "cradle to the grave" service:

> *"There is obviously an issue around the role of the Public Health Nurse. I mean they are triple qualified, they are a nurse, a midwife and they are a Public Health Nurse, so that's three qualifications they have all achieved. And they are very experienced and very valued, but they have been the panacea for health care in the community, if you've had a baby they come round and see you, if you have a leg wound they come and see you, if you're dying they may well have a very active role in the care of the dying as well. So they have this cradle to grave role and remit"* **(Nurse Adviser for Palliative Care and Older People, DOHC, L 13, P3)**

This quote reflects the extent of work the community nurse is expected to undertake and there is a suggestion within her words that there is a need for Public Health Nurses to be assigned specially to the area of older people and dementia.

Another theme which emerged following interviews with policy experts was the importance of public and professional awareness of dementia, the salience of team work in dementia care and that dementia-specific training should become a priority:

> *"Breaking down the boundaries between professionals, getting people to work better together, you know, some element of resources really, the whole stigma, education and training is a huge issue, proper education and training"* **(Care Group Coordinator for Services for Older people, L32, P16)**

One expert questioned the adequacy of care services and the quality of these services. He stated that there was a need for a new focus on continuing care. This view reflects those held by Marshall (1999: 91) who states that services for people living with dementia should be available locally from the earliest stages of the illness to the

end. Continuing care practices have proven successful elsewhere. Fortinsky et al (2002) examined the benefits of an 'Alzheimer's Service Coordination Program' for people living with dementia and their caregivers. Service Coordinators in this programme provided individualised non-medical consultation on dementia care and resources in the community. Benefits of the service were reported by caregivers, including positive outcomes in relation to symptom management and increased awareness of helpful community-based services.

The issue of advocacy in dementia care was also discussed with these policy experts. The premise of advocacy is based on the assumption that people living with dementia have the same substantive and procedural rights as other citizens (Cheston, Bender and Byatt, 2000: 475). In recent years, there has been an increased focus on advocacy[lx] and dementia (Cantley and Steven, 2004; Killeen, 1996). This has been mirrored in practice in Ireland with the appointment of an Advocacy Officer and an Advocacy programme run by the ASI. The involvement of people living with dementia in advocacy residents groups in Ireland also recently been addressed through a pilot study carried out by Begley and Marsh (2005). In terms of future policy development, advocacy was seen as a viable service:

> *"There is a need to ensure that people are supported in looking for the care and standards of care they want"* **(Former Director of the NCAOP, L20, P6)**

To improve service delivery and client care, further dementia-specific training for staff was a priority highlighted over and again by several of these policy experts. Therefore, education and training for people working in dementia care services was a perceived need. GP training in particular was considered critical since it was seen that GPs played

[lx] Advocacy is about 'making the case for someone or for a group of people or helping them to represent their own views, usually to defend their rights or to promote their interests. The concept has special relevance to people who are disadvantaged in some way, and as a consequence are less able to speak for themselves' (Killeen, 1996: 5)

a key role in relation to referral and were the gatekeepers to other services:

> *"GPs really are critical to it [referral]. They are often the first point of contact. I suppose there is huge work to be done with GPs certainly. If you look at Professor Murna Down's work in Bradford around the role of GPs, she has clearly identified that they're not really interested in this type of education...it's very hard to get GPs engaged. So there's [a] huge issue about their...knowledge base, about their referral pathways, about referring to Geriatricians...you know about the whole issue of stigma I suppose, the family may not want them referred, that they may refer to generic services... the big challenge is really trying to get GPs on board to refer people early enough"* **(Care Group Coordinator for Services for Older People HSE L10, P11)**

It was also felt by some that to provide higher quality care, service structures needed to change and this would also require an attitudinal shift:

> *"If we want to provide a person-centred comprehensive, capabilities-led service for older people with dementia then that is time intensive. And that requires a change in the structure of care; in terms of the number of personnel, the mix of staff, their education, their training, the level of engagement over a 24-hour day, seven days a week"* **(Author of An Action Plan for Dementia and Director of the Irish Centre for Social Gerontology, L11, P5)**

And a move away from the medical model:

> *"The majority of these people (with dementia) can live at home, the majority of these people can be actively involved, the majority of these people we need to try and reach as people*

> *rather than see them as patients all the time, and that requires a very different type of system and structures to be put in place"* **(Author of An Action Plan for Dementia and Director of the Irish Centre for Social Gerontology, L11, P5)**

This adherence to the medical model was also highlighted by another policy expert, who in referring to the role of GPs also hinted at the disadvantages people may experience if their needs are not exclusively of a medical nature:

> *"If they are seen by the GP, the GP refers them to geriatric assessment then they go back to the core community services and because, I suppose it goes back to the point that we are so hung up on physical need you know and if the person isn't incontinent, isn't x, y and z, then really we say sure come back to us when you have a problem"* **(Care Group Coordinator for Services for Older People HSE L25, P11)**

Proper care planning, where a person has an individual care plan and where there is an integrated approach to resource provision at community level were also mentioned by this same policy expert as key priorities.

8.4.2 Information

Policy experts acknowledged (in line with respondents and care-partners) the great need for information about services to be available for those affected by dementia. In addition, one expert stated that information was needed at both the 'micro' and 'macro' levels and in particular that demographic and up to date epidemiological data was needed in order to plan appropriate services:

> *"We need to know exactly you know how many people are out there, what is the prevalence rate and what is the incidence of dementia – upcoming demographic changes make such information critical to the planning process"*

(Author of An Action Plan for Dementia and Director of the Irish Centre for Social Gerontology L42, P2)

Whilst the data collected from people living with dementia and their care-partners demonstrate their quest for information, interviews with these experts revealed how policy developers also needed more information, but of a different type. Their information needs were related to issues such as quality of care, quality of life, and pathways through care:

> *"It starts at a primary care level, at a GP level. It starts at the Public Health Nurse level, at the community based level. We need more information on dementia in Ireland, particularly on the social aspects of dementia, the social framework. We also lack institutional information, how people with dementia are looked after; both at home and in long stay care. Whether they are given good quality of care: whether quality of life is prioritised. What do people think about their relationships, their connectedness to people with dementia when they are caring; how do you enhance personhood; how do you develop capabilities - all of these type of wider issues"* **(Author of An Action Plan for Dementia and Director of the Irish Centre for Social Gerontology L42, P20)**

8.4.3 Funding

As mentioned earlier, a key priority identified by several experts was the need for ring-fenced funding to be dedicated to dementia care:

> *"You can have the best policy in the world and have it absolutely up-to-date and referenced in every single way but you haven't got the money you can't move things forward. So I think unless we have sustained funding and that's a government decision so I suppose we have to wait and see"* **(Nurse**

Adviser for older people and Palliative Care, DOHC, L37, P9)

This point was reiterated by the CEO of the Alzheimer's Society and the author of an Action Plan for Dementia, who stated that resources for the care of people living with dementia should be quadrupled:

> *"I do think there needs to be a realisation that we are talking about increasing resources significantly; I would say a quadrupling of resources. We are talking about developing a different person-centred system getting more resources into the system is a critical issue"* **(Author of An Action Plan for Dementia and Director of the Irish Centre for Social Gerontology, L42, P9)**

8.4.4 Diagnosis and disclosure

No real consensus could be found amongst policy experts on the question of best practice in relation to the disclosure of dementia to the individual. However, a number of policy experts felt that a standard approach, where a diagnosis is disclosed to all people that present with dementia, should not be taken. Instead, diagnosis should be considered at an individual level:

> *"I would think first and foremost that you need to consider who you have in front of you, and once you have established in your own mind following a few sensitive questions what information you think the person themselves would welcome, then you follow that judgment."* **(Former Director of the NCAOP, L22, P7)**

> *"I think as a principle...diagnosis should be disclosed. There are individual situations where it's not feasible or wise. And my only fear in leaving it all to the medical profession is that not [telling] is the easy option. But I think as a matter of principle... if I was somebody with a dementia I*

> *think I would like to know as early as possible, in order for me to do something about it. So I think that as a working principle I accept that individual situations may differ..."* **(CEO of the Alzheimer's Society of Ireland, L31, P6)**

Others believed that a standard policy of disclosure should be adopted:

> *"Interviewer: Just on diagnosis would you think there should be standardised disclosure of diagnosis? Policy expert: I would fully agree really, the best way I mean, I suppose we have to look at the palliative care model, there was this huge discussion for years any person who was dying shouldn't be told. Interviewer: Shouldn't? Policy expert: That was the, you know, that in palliative care no, no we shouldn't tell them they're dying because they will die quicker or they will react very, very badly and I think we have now moved on where really the principle is that everybody should be told... I suppose everybody should be told because it will affect their life"* **(Care Group Coordinator for Services for older People HSE, L46, P13/14)**

A policy expert mentioned that one of the outcomes of there being no standard practice or no national guidelines on disclosure was that families were relied upon to disclose the diagnosis:

> *"The whole thing if you have a terminal illness you can't tell the person that they have the illness really, you tell the family... so there might be an element of protectionism as well. And I suppose there, I suppose all of those factors need to be taken into account"* **(Care Group Coordinator for Services for older People HSE, L41, P13)**

A rights-based approach was also advocated:

> *"In a sense public awareness, public attitudes, public expectations and so on about dementia would still, I think, be on the low side. People have the right to find out about the illness, have a right to make plans. In that way people may be able to plan for the future, plan their home life, family life, relationships. Dementia should not be hidden. It's not something that should be hidden from communities you know where people live"* **(Author of An Action Plan for Dementia and Director of the Irish Centre for Social Gerontology, L15, P3)**

One expert felt that diagnosis was not just about medical professionals deciding what was best practice, but a conscious move was needed to inform society on the realities of dementia and to develop policies inclusive of people living with dementia:

> *"I don't see why it should be hidden from people, so I would certainly think there should be openness. But that openness depends... not just on the one-to-one relationship between the General Practitioner or a Consultant or whoever is making the diagnosis that has to be embedded as in all these things, within a social structure, within a socio-cultural setting. Just because someone has dementia does not mean that they should be isolated and ostracised, that they are seen to be different"* **(Author of An Action Plan for Dementia and Director of the Irish Centre for Social Gerontology, L26, P3)**

Other statements by these key experts on disclosure mirrored the experiences of the respondents with dementia i.e. that having a diagnosis helped to 'legitimise' and explain their experiences:

> *"The diagnosis of dementia is important to carers because it explains the loved one's symptoms in terms of a sickness, which is more respectable*

> *than if the person were just considered to be 'barmy' or to have psychiatric problems. People with dementia suffer the stigma of old age as well as the stigma associated with psychiatric illness which makes them doubly vulnerable"* **(Former Director of Services for Older People, HSE East Coast Area, L35, P21)**

This is supported by findings in other research on stigma and dementia (Williamson, 2008).

Interview data (from all respondent groups) also suggested that there was a lack of appropriate referral pathways after diagnosis. Sometimes help and support was available, but due to lack of knowledge of its availability it was not accessed. One expert said that the role of his organisation (the ASI) after diagnosis was often not recognised and people could be diagnosed and then left with no supports:

> *"One of the challenges is that as a Society we're [ASI] not always recognised as being the people that should be contacted directly after diagnosis, people forget. But part of your difficulty is that you're diagnosed and then sent home and then what happens?"* **(CEO of the Alzheimer's Society of Ireland, L6, P3)**

This gap in service provision at the early stage of dementia was also recognised by others:

> *"If somebody is told they have dementia the next obvious question is what's going to happen to me. And if the response is well actually there is nothing we can do to help, actually just go home wait till it gets worse and you're not going to see anybody in the meantime then this is a really bad system. People need support at all levels and so do their carers. There are too many gaps at present, where people are left to their own*

devices" **(Author of an Action Plan for Dementia and Director of the Irish Centre for Social Gerontology, L26, P3)**

8.4.5 Section Summary

A number of key themes emerged from interviews with policy experts. One theme common to most was a call for a new strategy for older people to replace 'The Years Ahead Report'. Other themes included the need for (i) continued and increased funding if optimum health and social care is to be provided, (ii) the collection of accurate incidence and prevalence rates of dementia to enable service providers to develop the type of services needed, (iii) immediate support services to be available following diagnosis, (iv) more information services detailing formal entitlements, (v) more training for health care staff and (vi) overall improved professional and public awareness of dementia. Policy experts also felt people working in dementia care could learn a lot from other areas including the disability movement and palliative care. In particular, they could learn about the disclosure of a diagnosis and about the need to empower people living with dementia by keeping them well informed. Their commentaries and views clearly reflect their commitment to a rights-based approach in dementia care and their embracing a broader social as opposed to an exclusively medical view of the illness.

The interviews revealed how advances in the development of community-based dementia-specific services remain slow in Ireland. Agencies that provide the majority of dementia-specific services in the community are voluntary/non-profit based and there are no formal statutory dementia-specific care experts within older people's services who are working exclusively with people living with dementia.

Marshall (1999: 90) notes a number of key factors needed in the provision of services for people living with dementia – partnership, integrated care and holistic assessment. The maintenance of old

budgetary and geographical boundaries within the HSE, despite its recent development, has seriously hampered the national provision of services. As Convery (2001) points out: "there is a lot of exhortation on how this objective is to be achieved, but little guidance".

Policy experts called for the implementation of the policy recommendations already outlined in Ireland's main policy document on dementia. Interestingly, when evidence of any implementation did exist, this tended to be in the medical area in, for example, the expansion of old-age psychiatry and geriatric services. This is a good example of how dementia services continue to be medicalised in Ireland. Whilst it seems legitimate and acceptable to fund medical services, resources for community services do not appear to warrant the same budgetary or political attention. Policy experts also felt that policy development in dementia care and improved service delivery can only occur in a societal context and in a socio-political and economic environment that supports these developments. Therefore, to achieve an appropriate level of service provision increased public awareness of dementia is needed.

8.5 Policy Implications of the Findings

One of the core research questions posed in this thesis concerned the policy and practice implications of the lived experience of dementia. The above sections examined expert opinions on this issue and analysed their views about where gaps in policy existed at a macro level and what was needed to improve services for people in the early stages of dementia. The final part of this chapter focuses on the policy implications as voiced by the most important respondent group in this investigation, the person living with dementia. Each findings chapter is taken in turn and their policy implications are discussed.

8.5.1 Living with Dementia

Chapter Five demonstrated that the experience of having dementia was unique to each individual. There were common themes

emerging in the data collected from the men and women in the sample; however, dementia affected each person differently, with respondents reacting in different ways to the changes they were experiencing. This is partly due to individual and unique life histories, life experiences and personality. A common theme for all respondents, however, was the search for some kind of meaning to explain the changes they were experiencing, whether they acknowledged their diagnosis or had never been told it in clear terms.

Policy development for people living with dementia should support the person as an autonomous individual, giving him or her control. A key issue relating to control is awareness of the illness. But what is awareness and how do we conceptualise it? Findings from this thesis show that the person may not always have been aware of their diagnosis or their cognitive 'impairment'. However, virtually all were aware of some significant changes to their lives, whether these were changes in their relationships, in their social lives, their emotional responses to things, their confidence and/or their ability to do things. Nearly all respondents were able to describe the effects of dementia in great detail and many were aware of the effect their disability had on other people.

Another aspect of awareness was choosing whether to publicly talk about and 'face up' to ones symptoms or alternatively choosing to disguise them. This study has shown that people living with dementia often implement (psychological) coping mechanisms such as covering-up or motivated denial to help them cope with symptoms. On different days people could be more or less motivated to do this. This type of awareness could fluctuate and it did not necessarily adhere to the principle of decreased awareness as time progressed. In fact, some respondents presented with what one could perceive as low awareness one week but the following week talked openly and insightfully about their experiences. People living with dementia, in common with everyone else, also have good and bad days. This

suggests that service providers should invest in ongoing and long-term contact with the person with dementia.

Investigating levels of awareness is important. Service providers can often unconsciously dehumanise the person with dementia when they have a poor understanding of their awareness. This occurs when the assumptions is made that the person living with dementia automatically has no insight (Hutchinson, Leger-Krall and Skodol Wilson, 1997: 1407) or no capacity. This in turn can lead to poor standards of care and the exclusion of the person from discussions about their future (Howorth and Saper, 2003: 120). Knowledge of the person's level of awareness can also inform care plans, particularly in relation to the person's ability to manage the illness. Therefore, to fully investigate how people living with dementia cope and how they can be (psychologically) motivated to deny the presence of a disability demands greater time resources and a flexible approach to individuals.

Data presented in this thesis also shows that some respondents were aware they would experience further deterioration. A common response to this was fear about the future. However, the vast majority of participants had little information about their prognosis. Whilst it is likely that this type of information was never discussed with them, the possibility of their having being told about their prognosis and forgetting cannot be out-ruled. Non-the-less I feel that relevant and comprehensive information about dementia and about prognosis should be offered to people when and if they want it. This offer should be ongoing, as the person has the right to change their mind and need for information may vary over time. The information should be made available both orally and in written format, communicated in a way which is easy to understand being cognisance of the difficulties some people with dementia have with communication. This may require create ways in how people are informed and in how we understand the preferences and needs of people living with dementia.

One of the findings of this research was that a number of respondents made sense of changes they were experiencing by blaming themselves for what was happening to them. Access to information in these cases may have helped to dispel such misconceptions. Loss of confidence was also experienced by some and this loss of confidence was sometimes related to not knowing what was happening around them - Mrs Curran for instance got lost coming home one day (she was never told her diagnosis) and as a result she lost confidence in going out alone.

Kenny (2008) presents findings on loss of confidence amongst older adults who experience unexplained falls. However, Kenny states that once a cause is established a legitimate reason is provided for the changed behaviour and confidence may well return. It is therefore important that practitioners also dispel these beliefs, reacting sensitively to the person. This would support the argument for adequate disclosure of diagnosis so that appropriate information can be given about the cause and treatment of dementia. Due to the varying levels of information needed and the fact that some people may not want to know about their prognosis, the extent and level of information to be given should be assessed at an individual level. This reflects a person-centred approach to dementia and promotes autonomy and respect. Provision of knowledge facilitates the person's control over the situation and supports Marshall's (1999: 87) assertion that people living with dementia should retain as much control as possible over the support they receive.

Findings from this study show how quantitative and qualitative methods of questioning elicited different responses particularly around awareness of memory and cognitive disability. When respondents were asked to rate their memory problem on a scale from very bad to very good, in general they gave positive responses. However, through qualitative questioning, the reality was revealed to be quite different. Respondents spoke openly about their memory and cognitive disability, describing symptoms in great detail. This suggests that qualitative approaches can be more successful in

gaining a full insight into the processes which the person is experiencing. This also suggests that more successful outcomes can be gained as a result of talking about the effects of the disability (such as symptoms) rather than dementia itself.

Results from this research show how spouses and other family members were often the first to notice the early signs of forgetfulness and cognitive change. Therefore, people who live alone or have smaller networks are at risk and more vulnerable in relation to their advancing further into the illness before seeking or receiving a diagnosis. This suggests that greater attention needs to be given to those who have smaller social and fewer familial networks. Investigating social contacts and networks should therefore be part of any psychosocial assessment of need.

Another finding emerging from the research was that there was an expectation amongst respondents that physical deterioration and significant memory and cognitive impairment were a normal part of ageing. This could be due to a lack of awareness of dementia amongst the general public. Negative portrayals and images of dementia and inherent ageism in society can contribute to stigma which also affects people seeking out a diagnosis and a person's acceptance of a diagnosis. A policy expert stated in an earlier section that policy and practice occur in a societal context. People living with dementia can often contextualize their experiences and the early signs and symptoms of dementia believing them to be associated with the normal ageing processes, this may have an effect on how service providers assess the person. This can also have an influence on their seeking out a diagnosis and looking for rehabilitative and psychosocial interventions to support their quality of life.

Findings on the lived experience illustrate how most respondents put in place coping mechanisms. In many cases these were immediate reactions to the symptoms of the illness, for example keeping a diary and the use of visual prompts to aid in communication. Some

implemented strategies such as covering-up. Others were very open about their diagnosis. Each person implemented their own strategies and although there were common themes across the sample, such as the use of humour, specific strategies worked better for some than others. This further supports the argument that approaches and interventions need to be flexible and respond to the individual.

There is growing evidence (e.g. DASN International) that a common coping strategy for people living with dementia is to engage in peer support. Interestingly, respondents in this study did not want to talk openly with other people unfamiliar to them about their dementia. They also did not wish to seek out professional help of a counselling nature in this area. It could be argued that by not "going public" or by not seeking out the support of counselling services, they were further subscribing to the widespread myths and nihilistic attitudes held in our society about dementia. To speak out could mean the risk of being marginalised. However, an environment supportive of their concerns and issues and one in which lay people and health service professionals were better educated and informed about dementia might have enabled them to do this. The lack or inadequacy of this type of services in Ireland, and respondents' unfamiliarity with them, also naturally played a role in shaping these negative perceptions.

Findings also show that a period of adjustment was often needed for the individual diagnosed with dementia, giving them the space and opportunity to come to terms with the effects of their disability. This finding supports the view that continuous assessment and follow-up should be available to people who have dementia. Information should be imparted gradually and repeatedly, as often at the time of assessment and diagnosis people may be tired, shocked, angry and unable to grasp the full meaning of what is being told. Respondents who spoke about acceptance and understanding had high levels of support from care-partners, other family members and friends. However, respondents did not mention formal supports in this context. This suggests that there is room for service development in the area,

to assist people living with dementia in adjusting to a diagnosis and to the symptoms of the illness.

8.5.2 Social implications of having dementia

Respondents living with the early stages of dementia were well able to take care of themselves. However, findings from Chapter Six on the social implications of dementia show how many respondents were having increased contact with their families as a result of their dementia. In most cases this contact was daily. This suggests that care-partners and other family members would naturally progress to becoming the main providers of physical care to respondents if and when it was required. This trend is probably influenced by government policy in Ireland, which depends almost exclusively on informal care and where there are no statutory services available after hours or during the weekend. The organisation of many community-based services further exacerbated this trend, as many home help and care attendant services used by respondents did not cover weekends, certain holidays and often service providers' holidays coincided. There was a dependence on family members to provide or coordinate care at these times. A consequence of this is that people who live alone or have little contact with family and have smaller social networks can be at risk of inadequate care, social exclusion and premature placement in long-term care.

Findings from this study also illustrate that dementia was rarely experienced in isolation by the person themselves; it also had an effect on family member and close friends. There is no doubt that the family and friends of respondents were also affected and it can be argued that in terms of service development for people living with dementia, there is a need to develop integrated family support programmes. Dröes et al (2000: 102-103) describe an interesting integrated support programme based on an adaptation-coping model. The person with dementia along with their primary caregiver is supported in coping with the adaptive tasks needed to live with dementia. Existing services can then be adapted to meet the social and psychological needs of respondents and their families.

In one case in this study, contact with a social worker was made from within the hospital setting. However, only the care-partner was offered the service. A relationship-centred approach to the provision of social work service may have been more beneficial in this case, as findings showed that both people living with dementia and their care-partners were affected by the onset of dementia, often indeed in similar ways. Findings show how respondents often withdrew from broader social networks and there was greater contact with kinship groups. This affected the relationship respondents had with those closest to them, for example Mrs Buckley and her husband, although very close, never spoke about her diagnosis, and she felt guilty about how dementia was affecting him.

Results from this study show how families played a larger role in supporting the person socially as family members, especially visiting children, provided a valuable social contact to the person diagnosed with dementia. Similarly to the maintenance of friendship networks, policies should respond to the potential isolation of some people living with dementia and consider the companionship element of the familial relationship. Policies should make provision for this rather than continue to depend on families exclusively as personal care providers. Timonen, Doyle and Prendergast (2006: 205) state that Ireland has underdeveloped social and companionship services for older people. While home care services for younger people with disabilities often make provisions for leisure activity or 'quality time', this is not the case for older people receiving domiciliary care.

Findings from Chapter Six suggest that there are positive outcomes to maintaining friendships such as an increased sense of belonging, stimulation and self-identity. These networks were also a valuable support. Friendship networks were supported by routines, meeting on the same day in the same place each week. Innovative ways of maintaining friendship networks, throughout the life-course, need to be identified and fostered. The CEO of the ASI also suggested that

dementia-specific policies can borrow much from the disability movement. The current health and social care system neglects and fails to acknowledge the importance of social supports. The dependence on families to provide physical and personal care can adversely affect the dynamic of many care-partner relationships. It was noted in the data that more formal support from statutory services may have helped some care-partners to put aside more quality time to spend with their relatives.

Some respondents mentioned the need for space from their families, wanting to remain independent from them. Family members also had different levels of commitment and availability. Adult child care-partners often had competing demands on their time and other commitments. The assumption of the availability of family members to provide care is questionable and to respond to this requires consultation with family members and those who have dementia to work out a system that suits all stakeholders.

Findings also illustrate that positively coping with dementia was supported when a good relationship existed between the person and their care-partner as well as the care-partner having a good understanding of dementia. In cases where care-partners were not coping with the diagnosis or did not understand the symptoms their loved one was experiencing the potential for a negative relationship to develop was greater. It is important that indicators of positive and negative relations are examined. For example, findings showed that a positive indicator of coping well was talking openly about dementia and a negative example is the development of a paternalistic relationship between care-givers and care-receivers. Findings suggest that people should also be encouraged, should they so wish, to tell others of their diagnosis thus creating an open awareness context; this tends to have the most positive outcome.

As stated above, findings show that may of the men and women in this sample experienced changes which had an effect on how they viewed themselves. These changes included shifts in familial and

work roles and changes in their engagement socially with others. It has already been stated that a loss of confidence, particularly when respondent did not know why the changes were occurring, was a common theme. This suggests that programmes should be developed that address loss of confidence and self-esteem.

Findings show that while the respondents perceived a general decline in their social life, most reported the maintenance of some social and leisure activity. However, qualitative analysis of data identified both ageing (e.g. death of peers; reduced work related network) and dementia processes (e.g. forgetfulness, increased communication difficulties) as responsible for decreased social contact. Data show that when in company some respondents often did not engage in conversation the way they used to, letting social interactions happen around them. However, in many cases, home life, hobbies, interests and intellect were well maintained or only slightly changed. People living with dementia can be involved and can have input into society.

People living with dementia have the right to and in many cases in this study respondents showed they were able to maintain an active and a good quality of life. The continued participation of people in social and leisure activities is relevant at a policy and practice level, as they often have high levels of ability and can benefit greatly from social engagement which counteracts the possible social isolation that can accompany a deteriorating illness. Early stage symptoms of dementia are often manageable and data from this thesis show that people can and in many cases would like to continue to remain active. The importance of meaningful work related activity was highlighted by some male respondents in particular. One female respondent greatly enjoyed volunteering, and although she was the only person in this sample actively engaged in volunteering, volunteering programmes for people with early-stage dementia could be further developed to engage people in meaningful, worthwhile activities, bringing them into close contact with other people who have similar experiences to their own.

As stated earlier, some of the decreases in social contact reported by respondents arose as a result of the stigma of dementia and the fear these men and women may have had of having their symptoms observed by others. Stigma was also experienced by their care-partners through the reactions of others to their relative (e.g. withdrawing due to embarrassment and frustration). In this way the potential for the person to become vulnerable to social isolation increases. Service planners and policy developers are well placed to ensure that people living with dementia do not become socially isolated or excluded. Unmet social care needs can exacerbate social exclusion, where social exclusion marginalises and further disadvantages people both as service users and as citizens (Percival and Hanson, 2005: 190). In the context of dementia, the limited service provision that exists has been largely concentrated around the medical needs of those with a moderate or severe stage of their dementia; however, the needs of those in the early stages also need recognition.

Findings from this research show that respondents and their care-partners in most cases did not actively seek social service intervention and their psychosocial needs were for the most part neither known nor addressed by formal service providers. They tended to seek out service support only when a health or medical problem arose, often by way of a crisis. Changes in respondents' involvement in social activity often occurred following a critical incident, such as getting lost and/or disoriented. This led to a lack of confidence which created increased reliance on care-partners and other family members. The role that assistive technology might play in helping people with day to day practical problems such as getting lost in familiar suburbs or mislaying important items in the home was not explored by service providers or respondents themselves or by their care-partners. It could be argued that respondents and care-partners would not have been aware of the potential of assistive technologies in combating these symptoms. Instead, the response was often one of withdrawal or the cessation of the activity.

This would suggest that the adverse effect of critical incidents such as these could be reduced if service supports were available and sought out, or if the person was made aware of the cause of the incident and the fact that the problems encountered were illness related. This reinforces the need for a continuous disclosure of a diagnosis and for follow-up support for people who receive their diagnosis. Diagnosis should not mean merely a one-off encounter but the person should have a number of contacts with the service provider. There were also examples of care-partners restricting the independence of the person with dementia following a critical incident. In one case, a respondent's spouse decided that her husband should no longer go out alone following his becoming disorientated while driving home from the shop. The reason, however, that he no longer went out unaccompanied was never fully explained to him.

8.5.3 Use and experience of formal supports

Chapter Seven examined respondents' experiences of using health and social care services. Overall these men and women used very few social care services. The most frequent and continuous contact they had with a service provider was with their GP. Another key service provider for respondents was the Public Health Nurse - six respondents had contact with this service. However, from listening to their stories, it seems that access to the PHN service was almost always based on medical needs and as most of these men and women enjoyed reasonably good physical health, most (11 people) did not 'need' this service. In three cases respondents had seen the PHN only once. Interestingly in another case when the PHN retired the service was discontinued. Those few who had received visits from the PHN were very pleased with the service and in one unusual case the PHN was coordinating other services for the person, thereby acting to some extent as a Case- Manager.

Baldwin (2008: 223) states that people living with dementia can be denied opportunity through institutional arrangements and practices that restrict social networks. Findings have shown how important

social networks were to people living with dementia but what part did institutional arrangements have in restricting agency and opportunity? The fact that PHN involvement was almost exclusively based on medical and health needs, rather than on psychosocial needs warrants further consideration. As the data show many of these people along with their care-partners had information needs and other psychosocial needs (Kitwood, 1997) such as the need for occupation, engagement, stimulation and for their self-identity to be reinforced. These needs often remained unmet since the view was held by respondents, care-partners and indeed later reinforced by policy experts that the PHN service was already over-stretched and when these service providers called to their homes they were under pressure with their time. Therefore any prospect of extending this service to cater to people's non-medical needs seemed unreasonable. In other countries such as the UK and Australia, nurse specialists (Admiral Nurses operate in a number of areas in the UK) are assigned to dementia care in the community and take a dedicated interest in the holistic needs of people living with dementia. The findings from this research suggest the need for this type of nurse service to be available in the community in Ireland.

The data from this research shows that whilst there are community-based Occupational Therapists, assigned to certain areas in Dublin, people in this research were obliged to wait prolonged periods for the service, sometimes up to two years purely to receive an assessment. Two respondents (N=2) therefore bought in this service privately. Three of the five people who had accessed the service had a once-off assessment and a home adaptation was carried out. In one case where OT services were accessed over a longer period, this happened at a Day-hospital and involved memory support training and rehabilitation which proved to be very beneficial. It seems that this type of rehabilitative support would be beneficial to many more of the people in this research who were living in the community. For example the people in this study who had experience getting lost in their community, those who had difficulty with time orientation, others who were forgetting and mislaying itmes, the care-partner

who was unsure whether she should discuss her concerns with her husband or hold off when the programme about dementia featured on the television, all of these people could have benefited significantly from the professional help and advice an occupational therapist (or a social worker) could offer.

Yet, ironically, it could be argued that the respondents in this study were a 'privileged' group within the current health and social care system in Ireland. Through the medical out-patient department they were attending, each was closely connected into a hospital structure and into a service system exclusively dedicated to the care of older people yet few received formal social care support. Instead they benefited from specialised medical knowledge and treatments at the outpatient clinic, for example, the vast majority were on anti-dementia medication. However, within this system no standardised approach for the assessment of dementia was used and doctors varied in how they interacted, assessed and dealt with people who presented with dementia, and especially in how they disclosed a diagnosis.

A few people in the study reacted very negatively to the news of their illness; they became angry and felt that they were being misdiagnosed. Some felt their behaviour was being scrutinised especially when asked to do a memory test. This reaction suggests that they needed more dedicated support which was not available. They were a sub-group for whom communication of dementia needed to be done in a very sensitive way. These findings suggest that training on best practice in relation to the disclosure of a diagnosis of dementia should be given to all service providers working in the care of older people particularly to GPS, PHNs, OTS, non-consultant hospital doctors along with other frontline medical staff currently working in older people's services.

In relation to the debate on disclosure, an initial inclusion criterion for this research was that respondents had to be aware of their diagnosis. However, as the research progressed and it became

apparent that full medical disclosure was not common practice then this criterion was amended to include people who were aware that they had a memory and cognitive disability.

Ireland is one of the few countries in Europe which has no guidelines on dementia diagnosis and disclosure. Most of the men and women in the research had only been told about their illness in 'softer' words or in non-threatening ways as for example the fact that their memory was not working as well as before. Often it was left to care-partners and family members to spell out words like dementia or Alzheimer's disease and the onus was not on the doctor to do so. This suggests that there is a need to develop approaches to disclosure which are mindful of the preferences and best interests of those with dementia. Initial diagnosis needs to be followed by further appointments shortly after a diagnosis, with frequent contact following to ensure the person is coping and has the opportunity to ask questions and seek answers. These meetings could be used to address any questions and concerns the person might have and allow the person to meet with a key worker from the community (e.g. case-manager/worker) who would facilitate the coordination of their community based care. A care/case manager approach has been advocated in the literature (O'Shea and O'Reilly, 1999). Those who disclose a diagnosis need to also be aware of the emotional reaction a person will experience after receiving a diagnosis, support may be required after this. Findings from this study showed that the clinical setting in which some respondents were told their diagnosis was not supportive or indeed appropriate.

There are also no guidelines in Ireland on prompt, holistic and continuous assessment once dementia is diagnosed. With the exception of a GP, there was no one service provider with whom respondents had consulted with regularly since receiving a diagnosis. It could be argued that outpatients was continuous but contact there was usually only six monthly or annually and whilst in general the service was well received, there was a view held by several that it was overstretched and involved long waiting lists. One respondent

mentioned that he would like to have had a key worker, someone to call in on him to ensure he was doing well. Dementia experts interviewed for this thesis highlighted the need for continuous care services. Findings show how those who received a diverse range of services had someone coordinating their care, in Mr Moore's case (see chapter seven, section 7.3.1) it was his daughter and for Mrs Martin (see chapter seven, section 7.3.1) it was the PHN. This implies that people living with early-stage dementia may find self-referral or the coordination of their own care difficult. An admiral nurse or case manager service would have been beneficial to a) inform on entitlements and b) coordinate interventions for them.

Policy analysis for this study showed how dementia-specific services were largely provided by the non-profit sector, namely the Alzheimer Society of Ireland. However, not all respondents in this sample were using ASI services, which is the largest service provider of dementia care in the country. There were a number of reasons for this low take-up: (i) as the CEO stated there is no automatic connection between receiving a diagnosis and contacting their service, (ii) respondents often had to depend on others to contact the ASI for them as they were not able to do so themselves, (iii) care-partners, although aware of the services, often delayed contacting them because they did not see their situation as critical enough, (iv) the ASI had limited provision of services for those in the early stages of the illness. However, this is being addressed by the organisation and in recent years greater emphasis is being placed on the person with dementia. Findings from this study show that it would be extremely useful if information about the ASI was given to people at a follow-up meeting by the person who disclosed the diagnosis. The ASI also needs to identify gaps where they can provide services to people in the early stages of the illness. One care-partner had contacted the ASI and was waiting on further follow-up as the initial support they offered (home respite) was not conducive to his or his wife situation.
Data highlights the lack of appropriate psychosocial interventions for respondents. Interventions that existed such as Day Centres were for the most part viewed very negatively by the sample, and the general

opinion held by most was that Day centres did not meet their needs. One issue was that respondents did not necessarily want to attend Day Centres with people in the much later stages of dementia and there was an absence of other social outlets for them. There is a need therefore to provide appropriate psychosocial interventions and other therapies that support and facilitate the person's continued well-being, stimulate the person and engage them in meaningful activity. As previously stated, meaning was very important in relation to the type of activities, engagement and participation respondents enjoyed.

One of the conclusions of this thesis echoes the argument of Van der Roest et al (2007: 560) that "Since there still is no cure for dementia...people living with dementia require a drastic adaptation of the health care system". Currently in Ireland people with dementia can fall through the cracks between older persons' services, disability services and mental health services. Therefore, based on findings from interviews with respondents and care-partners for this thesis it is suggested that older people's services should include a specialist in dementia (person-centred) care and all front-line staff should have adequate and appropriate training in dementia. It is important that people who receive a diagnosis are automatically referred to appropriate services. The new service structure should provide clear and coordinated pathways through care. **Strong links** between community care service providers and secondary care service providers would allow for the development of holistic and bio-psychosocial **care plans** to be developed for each individual. Case managers could also act as a one-stop-shop for individuals and they therefore would not have to manoeuvre through the complex health and social care system. Case Managers/workers, would also allow for continuous assessment of each individual and could act as a reassurance and support to families and to the individual using the service. The case worker would be in a position to monitor any changes in memory and cognition the person experiences and suggest the implementation of appropriate psychosocial interventions (e.g. memory training, cognitive stimulation therapy,

assistive aids and home adaptations (OT), art and music therapy other auxiliary services (e.g. counselling).

A new system of care for dementia should have a strong emphasise on **rehabilitation in the community**, where the person's social, psychological, emotional and practical needs can be assessed and service supports put in place to address them. OT services in the community would include assistive technologies, home adaptation, and memory and cognitive support training (as this worked well for the respondent in this study who received it). Interestingly this was only offered to respondents in this study through the hospital and was time limited lasting only ten-weeks. Findings from this study support the need for the development of programmes that provide meaningful activity for people with early-stage dementia. A key worker working alongside the person with dementia could help to identify strategies for their continued **social participation and engagement.**

The first point of contact for many people with dementia is their GP. However, an age-related or older persons' Social Worker[lxi] or a Nurse Specialist (for example a Public Health Nurse who has specialised in older person's care) would also be well placed in the community to respond to people who are displaying the early signs of dementia.

Findings showed that respondents and care-partners were glad to be connected to the hospital Outpatients. This may have been the result of a deficit of services in the community. Currently Age-related care teams[lxii] (usually) comprise of two consultants, one senior registrar, two interns, clinical nurse managers and a specialist nurse trained in domiciliary assessment, stroke and falls. To address the needs of people living with dementia I would suggest the inclusion of a

[lxi] Recently 32 elder abuse case worker posts have been established throughout Ireland. However, there is no generic social work service operating in the community.

[lxii] The example given here is the Age Related care team in which all respondents in this study were linked to. The precise composition of care teams varies from hospital to hospital.

dementia nurse specialist in these care teams and the inclusion of other front-line staff with specialist interest in dementia.

8.6 Respondents as a Collective: The Citizenship Model

The above sections summarise the main findings in relation to their policy implications. Interpreting this data further and applying the citizenship model as lens in which to view these findings provides insight into the potential for people living with dementia to effect change at a personal and political level. Innes (2002: 490) states "dementia and dementia care have historically occupied a low position on the political agenda ... the absence of a powerful political lobby or forum may have contributed [to this]". Quotes from policy experts presented in this thesis support this statement, as until very recently there was a low level of interest in older people's issues at a political level in Ireland. Another example of this is that none of the sample were part of a political lobby or forum of people living with dementia. The person living with dementia can have agency under the citizenship model, by being part of a collective they are empowered and the provision of civil, political and social rights is achievable. Similarly to other studies (Cheston, Bender and Byatt, 2000: 473) findings from this thesis show that when respondents expressed interest in meeting other people with dementia it was for social contact rather than as a political forum for self-advocacy.

Bartlett and O'Connor (2007: 107) highlight a difficulty with the citizenship model and dementia as it presumes a person's self-cognisance to exercise their rights and responsibilities. In relation to self within a collective, it is true to say that the majority of respondents were not self-cognisant of these. What can the findings of this thesis tell us about the obstacles that existed for respondents in relation to this point? Nearly all respondents were managing on a day-to-day basis. They coped well with the changes dementia presented, often using humour and practical coping mechanisms as a response. However, the long-term management of dementia was not generally considered. First of all, not all respondents were aware of their

diagnosis, in this way they did not know that they now had admittance to a new 'social group' as someone with dementia and as a result did not seek the company of other people in a similar situation, someone also diagnosed or experiencing the symptoms of dementia. Others did not know their prognosis and therefore in the main hoped to maintain the status quo or 'life as usual'. When peer support or engagement with other people who had memory loss was mooted by me during interviews, the majority of respondents did not wish for this (it should be noted that a small number did, but as already stated they expressed this in relation to a desire for more social engagement generally).

There were a number of reasons presented in the findings chapters to explain why respondents did not want to engage with other people who were experiencing similar experiences. These were largely based on the meaning of dementia for each individual (as presented in section 5.5). These can be summarised and interpreted as (i) continuance of the social actor (presenting a positive front) and (ii) maintaining role and identity - the latter category is further broken down into (a) covering up and normalising, (b) maintaining space, and (c) withdrawing.

A lack of confidence and the dominance of the medical model also had an effect on the place of the person within the collective. Many respondents reported a lowering in their self-confidence and the effect of symptomatic experiences often resulted in self-imposed restrictions on their lives as a result. Findings therefore show that people were prevented from maximising their abilities. Innes (2002: 494) states "If personhood is maintained, a sense of social confidence, worth, agency and hope will have been preserved for the person with dementia. In simple terms this means that a person with dementia will be confident to engage with others, will feel valued and accepted by others, be active and participate in activities that have personal meaning and will retain a sense purpose". This suggests that many respondents did not feel the benefits of the maintenance of personhood.

The dominance of the medical model does not support the person living with dementia as someone with power and agency. For example, social constructionists (Harding and Palfry, 1997) question the unequal knowledge base between the medical professional and the person who has dementia. Findings showed that a minority of respondents were told their diagnosis, the majority were told in softer terms that they had a memory problem. The clinical setting in which some respondents were told their diagnosis was not conducive as a supportive environment to explore the diagnosis with a professional. Findings showed that many respondents had questions about their current experiences, what would happen to them in the future and what their rights and entitlements were. This unequal knowledge base excluded the person from any discourse around the provision of their care (Innes, 2002: 485). This has been noted within the disability movement as professional values and objectives where seen to define needs and practice (Barton, 1994: 235). I argue that this has also been the case in relation to dementia care practices in Ireland. In many cases respondents sought explanations for what was happening to them. They had many questions about their diagnosis and prognosis, what would happen to them in the future. These basic needs for information and explanation (as well as reassurance) were often unmet.

These reasons all contribute to the explanation why respondents were not part of a collective, which would have given them greater agency to assert power over decisions made around dementia at a service intervention level and at an interpersonal level with their family and friends. Inclusion in groups implies belonging and having rights within the group. However, because respondents were not engaged with other people living with dementia there was no collective action on the issue and they did not benefit from what Clare, Rowlands and Quin (2008: 18) call collective strength.

8.7 Directing the Development of Formal Services

It is argued that unless we have a community care system which encourages and engages people with dementia, any policy changes will not work (O'Shea, 2008). There are two implications to this; the first is that we need to consult with people living with dementia, which was one of the main aims of this thesis, adhering to a person-centred approach. The other implication to O'Shea's statement is that community care needs to focus on people's abilities so that they can engage and participate. The development of a citizenship model of dementia enables people living with dementia to be empowered and included (Baldwin, 2008: 222). It involves power and citizenship in practice; thus linking the individual and policy (Baldwin, 2008). Part of this is then consultation. The citizenship model asserts that: (i) people with dementia can and have a lot to contribute to society, (ii) people with dementia have rights and responsibilities (in this context to contribute) and (iii) people with dementia are the experts (Marshall, 2007). Findings show that respondents were able to express themselves and give insights into what it is like to have dementia and highlight the deficits in the system. Findings have also highlighted the types of interventions people sought; where activities had to have meaning to their individual lives.

Despite huge advancement in understandings of dementia this thesis has shown that a medical model of dementia still dominates in Ireland i.e. dementia is still seen and treated primarily as a progressive and pathological degeneration of the brain and the body, leaving little space or attention to the *person* (Davis, 2004: 369). The interventions respondents were offered were largely service provider's observations of their decline. Bond, Corner and Graham (2004: 231) outline four of the essential aspects of the medicalisation of dementia"

- expert control; the doctor has monopoly over medical knowledge. For example, findings from this thesis show that respondents received inadequate information, leaving them in

many cases bewildered and worried and reliant on other sources for information.

- social control; the medical professional has the power to legitimise the social status of normal or pathological. Findings from this thesis show that in the majority of cases respondents had not been told their diagnosis and often normalised their symptoms by comparing themselves to others.
- individualisation of behaviour; solutions are not sought within the broader social context, leading to individuals blaming themselves. Findings showed that in some cases respondents sought meaning to what was happening within the confines of their own actions (self-blaming). Inattention and laziness were key themes identified by respondents as a cause of their memory loss.
- de-politicisation of behaviour; ignoring the meaning of behaviour that goes beyond cognitive loss. The lack of follow-up when a diagnosis was made shows that there was little cognisance of the emotional, psychological and social implications of receiving a diagnosis.

A serious consequence of these factors is that they ultimately reinforce social exclusion (Bond, Corner and Graham, 2004: 231).

Barton (1994: 239) speaks of the fact that some people with disabilities are not part of the organisations of disabled people and some have a less critical view of the role of professionals in their lives. It has already been established in this chapter that respondents were not part of a collective or organisation with other people living with dementia. Where criticisms of professionals were made they came from care-partners, usually daughters of the person living with dementia. In a number of cases respondents expressed dissatisfaction with aspects of the care they received, but generally countered this by praising other professionals' engagement. This suggests that there is generational variance in expectations of care/service.

8.7.1 Expectation for service intervention

A number of reasons for this generational variance in the expectation of service and formal supports can be drawn from the data and from the policy review undertaken in Chapter Three. The development of formal care services in Ireland was strongly influenced by the Catholic Church (Timonen, Doyle and Prendergast, 2006: 35). This fostered a culture of voluntary or non-profit sector care provision. In this way respondents and spouse care-partners could have perceived services provision not as a right but as a privilege and therefore appreciated the services they received without examining any deficits in provision.

Another reason for low expectations of care/service can also be attributed to respondents' and care-partners' assumptions and expectations of older age, which reflect, and mirror an inherent ageism in our society. They often expressed an expectation of lower quality of life in older age where disability and memory loss was to be expected. This had implications on their seeking a diagnosis and any interventions subsequently; respondents and care-partners often waited until a critical incident occurred before going to key service providers.

A further reason for low expectation is the quality of the service they received. Often this was underpinned by professional stigma and the perceived lowered expectation of older people. In one case (Mr Burns) a respondent approached his GP about experiencing loss of memory. It was dismissed as normal ageing at the time but Mr Burns subsequently received a diagnosis of Alzheimer's disease a year later. This example provides some insight into how the negative connotations of ageing are supported and reinforced by health care professionals.

8.7.2 Relationship with the system

Findings provide valuable data on the relationship people living with dementia had with the broader health and social care system. The basis of this relationship can be broken down into: (i) the type of

model that exists in Ireland (predominantly a medical model); (ii) incentives and currency needed to engage with services (presence of physical ill-health); (iii) diagnosis (or lack there of, as already outlined) and (iii) their relationship with service provider.

The provision of services and interventions exist with a health and social care framework distinct in every country. There is currently no systematic approach to addressing the needs of people living with dementia in Ireland. The main aim of policy and practice should be to maintain and promote the quality of life of all stakeholders in the dementia process. These include those with the illness, their supporters (family, friends, and neighbours) and formal service providers. The Irish system differs from the systems in existence in many other developed countries, as there is:

- heavily medicalised model of health and social care
- no guidelines for service providers on the disclosure of a diagnosis of dementia
- high dependence on informal care
- no legislation underpinning social care and hence no right or entitlement to it

The findings of this thesis reveal the medical and physical focus of current service provision in Ireland. This is exacerbated by the fact that community-based social care is not legislated for, whereas health and nursing care (hospitals and nursing homes and public health nursing) are under particular legislation acts. Other reasons why participants were not using services were that (i) they did not perceive their situation as critical enough, (ii) they never used social services before (iii) they did not know their current entitlements and (iv) there was a stigma attached to using social services (similar to the finding by Morgan et al, 2002: 1133)[lxiii]. Psychosocial interventions that were available were viewed negatively (Day Centres) or were unfamiliar as the respondents had not been referred to them (Day Hospital and/or Occupational therapy). Full assessment, rehabilitation

[lxiii] These authors describe stigma as "the concept of stigma involves attitudes, feelings, and behaviours, and implies a negative label being placed on an individual or group that manifests itself in prejudice, discrimination, fear, distrust and stereotyping" (page 1140).

and appropriate care plans were also not made available to the any respondents.

Findings showed that respondents were low service users. They were in relative good health and as a result had little contact with formal service providers (see Table 7.1). In this way they did not have the appropriate currency (physical ill-health) in which to engage with the system. This was because service interventions generally focused on physical health and well-being over mental health and well-being. As a result respondents and care-partners were waiting until something critical happened or the person's health deteriorated before seeking an intervention. This thesis has highlighted the medical nature of health and social care services for people living with early-stage dementia in Ireland. This excessively medical focus can lead to inappropriate interventions being offered to those with dementia, and perpetuates the attitude of many that interventions should only be sought when there is a physical manifestation of disease. This model needs to be challenged (i) so that people can better understand the nature of dementia, with its social and psychological implications and (ii) so that services are developed that are meaningful for people.

Findings showed that for respondents there were no natural referral pathways for them. There are few dementia-specific services that they can be referred to. Findings suggested that systems of referral are very subjective, dependent on the knowledge and inclination of service providers. Some respondents were referred to additional services while others were not. These findings further reinforce the need for dementia-training for frontline staff in health and social services. Respondents received varying levels of care based on their doctor's knowledge and practices. There was no follow-up system for those that had received a diagnosis. One of the few opportunities they had to ask questions about their prognosis was at the time they were diagnosed. Participants who remembered being given a diagnosis found it difficult to absorb the information and to take the opportunity to consult with the doctor about their illness. Respondents

and care-partners often did not know what their entitlements were as the majority did not receive consultation with a social worker.

The research also identified a gap in appropriate and widespread psychosocial and rehabilitation interventions for people with (early-stage) dementia and their families (and other informal carers/supporters). Findings from the study demonstrate that people with early-stage dementia and their care-partners and family members could clearly benefit from and in some cases were actively seeking formal supports of a non-medical nature, including some very basic provisions such as information but also other services such as a key worker (case manager) and a social work/counsellor would also have been beneficial. There is a need for more psychosocial interventions to be developed complementing the current medical and neurological model of service delivery. Interventions need to have meaning for respondents e.g. day centres had negative connotations and if person already have a social network they did not perceive it to be useful, as attending a day centre reflected a loss of independence for respondents. This is also clearly an area that calls for further investigation as at the moment in the Irish context (and also in many other countries) we have a very limited understanding of what people with dementia themselves want by way of formal support and 'what works' from their point of view.

8.8 Chapter summary

A key issue discussed in this chapter is the way in which Irish government policy relating to care of older people, including care of people living with dementia, reflects a strong commitment to community care. Yet despite the rhetoric of community care policy, few of the recommendations highlighted and reiterated in various government reports on care of older people have been implemented. For community care services to be rolled out and operationalised at a national level significant funding is required and this is a key issue which needs to be addressed. The HSE is three years in existence; however, the old health board system of regional

budgets has not been fully phased out, and local health offices continue to control their own funds. This hampers the national implementation of many services meeting the needs of people living with dementia.

The current system of health and social care services places little emphasis on agency or power; two integral aspects of the citizenship model of dementia. Those involved in this research were often not explicitly told their diagnosis but rather news of their illness was conveyed to them in cryptic terms – many being told that their memory was "not as good as before" or "problematic". At the time this news was being told to them, little opportunity was afforded to explore these issues with a trained health service professional. There was very limited scope for respondents to ask questions such as how bad will it get, what can I do to avoid embarassing situations, who should I tell, is there anything I can do to avoid further deterioration? In cases where a social work service was offered (two cases) it was largely to address the needs of care-partners and their relatives were not included in the process. There is potential for the Social Work role to be broadened out into a relationship centred approach, as findings have also shown that dementia affects both the person and those closest to them.

Many of the men and women involved in this research along with their care partners had significant information needs which remained unmet. They had questions about their dementia, their entitlement to services, their prognosis or what would happen to them in the future. Getting information on what services were available to them was often dependent on who they spoke to informally and there were few clear pathways through care available to them. None of the respondents had worked with a health service professional on the development of a care plan and there was little follow-up of these men and women once a diagnosis was given.

Findings however showed that there were some positive aspects to the current system of health and social care. For instance, being

linked into the Outpatient clinic offered some reassurance to both respondents and their care partners although the service it seemed was quite medical in its focus and was primarily concerned with monitoring the progression of the illness. In the few cases where respondents attended the Day hospital and received some rehabilitative interventions, they appeared to work well. I would also suggest that services could have worked better if they were available in the community.

Baldwin (2008: 227) poses the question "does the supporting framework of social policy and resources give incentives and impetus to new ways of engaging with people living with dementia so that they can participate as citizens?" This investigation has shown that the current supportive health and social care framework in Ireland does not provide people with new ways of engagement. One policy expert interviewed highlighted the need to consult more with users. Current national policy (Department of the Taoiseach, 2004) calls for more public consultation. To engage meaningfully with people living with dementia demands time and additional resources. This could be another reason why this does not happen in a larger scale[lxiv]. Part of agency is being given the opportunity to express oneself (Baldwin, 2008: 225). This investigation has provided valuable data on how to engage people living with dementia, it has shown that respondents were well able to give information on their lives and on the services they want and need, in this way leading into the development of responsive policy and practice.

One of the most striking findings of this thesis is the persistence of the medical model. As Baldwin (2008: 225) states the involvement of people living with dementia in research has resulted in their voices being heard to a much greater extent (as this thesis has also shown). However, people living with dementia are not involved in policy making. This is the first study of its type in Ireland which focuses on the

[lxiv] A number of small scale projects have been undertaken to consult with people living with dementia (NCAOP, 2007 - HAIRC; UCC, 2007 – Clonakilty study).

lived experience of dementia and people's experiences within the current system of health and social care.

Writing this chapter I had to consider how my own experiences and position on certain issues led to the conclusions drawn. For example, I believe in openness and individual autonomy as a principle. Recognising this I had to ensure that the data led to these conclusions and that they were not based on my own views but rather were very much informed by the key informants in the research. The policy implications emerging from this work suggest that Ireland is still only in the embryonic stages of developing health and social care services for people living with dementia. There are few dementia-specific services available and within generic services there is little specialism in dementia care. Currently little is being offered in the way of formal supports to those with the illness.

In conclusion, findings from this study have also shown that respondents by and large managed very well on a day-to-day basis. They were resourceful and applied and adapted innovative and positive coping mechanisms developed by themselves, such as the use of humour, maintaining domestic activities or continuing to partake in social/leisure time activities. In the main they were content, attempting to maintain as normal as possible a lifestyle. Some became distressed when they thought about the future, or when they reflected on the impact their dementia was having on others and how other people were affected by this. I would conclude that interventions should be developed which would help people maintain a good quality of life through supporting them within social networks and activities, as these were extremely important to them and care-partners maintained that contact with others has a positive impact.

CONCLUSION

9.1 Introduction

This thesis has provided insights into the lived experience, the health and social care needs and utilisation of services of a group of people living with early-stage dementia. It has linked the personal to the political (Baldwin, 2008: 222) by placing their experiences within the framework of the Irish health and social care system, hence embedding the personal, lived experiences within the systemic context.

This chapter concludes the thesis by addressing, in brief, the six core research questions and by elaborating on the conceptual and theoretical implications of my answers to these. This thesis set out to explore (1) the subjective meanings and experiences of dementia; (2) the social implications of having dementia; (3) the current service provisions for people living with dementia in Ireland; (4) the ways in which people living with dementia access services and interventions; (5) the policy implications of this investigation; and (6) the most appropriate ways of including people living with early-stage dementia in the research process. The chapter also highlights the original contributions of the study and some topics that require further research. Reflections on my own role in the research process and in the formulation of conclusions are embedded throughout the chapter.

9.2 Original Contributions of the Thesis

In recent years, the number of research projects that have attempted to hear the voice of people living with early-stage dementia has increased. In the Irish context, this study breaks new ground in an area never previously explored and contributes to a small but emerging body of literature on dementia which is inclusive of the views of people diagnosed with dementia. Within the

international context, too, this research has considerable originality and merit as in addition to investigating, in-depth, the experiences and views of people with dementia, it also explored the testimonies of care-partners and took on board the views of policy makers and key stakeholders working at a senior level in this field.

This thesis placed the lived, felt experiences and needs of people living with early-stage dementia within the broader context that encompasses both their informal relationships and the system of service provision. It is one of the (to date) very few investigations that have taken this approach and is certainly the first one within the Irish context. Herein lies the strongest original contribution of the thesis: its ability to analyse the interaction of the 'micro' and 'macro' levels in the dementia experience. Due to this multi-dimensionality, this study has been in a position to provide, for instance, unique and original insights into why people living with dementia and their care-partners did not utilise formal services. While this study was conducted in Ireland, there are good grounds for hypothesising that similar findings could be made in other countries that have under-developed service provision for people with dementia. My work can therefore in many ways be seen as a response to the lament by Innes (2002: 493) that although people with dementia are being included more in research, the statements of people with dementia are rarely analysed or related to the services they use – their voices are being heard but their voice not widely used to assess the quality of service provision. It is important to not just seek the views of those using services but also consult with those who do not. This thesis avoided these common pitfalls and hence was able to yield a more multi-faceted picture of the service landscape and both the strengths and inadequacies therein.

Findings on the application of the citizenship model of dementia have great original merit as they illustrated how the dominant health and social care structures prohibit the realisation of the benefits of the citizenship model for people living with dementia. For example, findings from this thesis show that respondents were not cognisant of

many of their rights (an important aspect of the citizenship model). This was due to a lack of a diagnosis (in most cases), inadequate information, a lack of individual confidence and the dominance of the medical model. These all had an effect on the place of the person within a broader collective of people living with dementia. The findings illustrated, over and over, how the people who took part in this study were prevented from maximising their abilities by the 'macro' structure. The analysis demonstrates how the dominance of the medical model does not support the person living with dementia as someone with power and agency.

9.3 Conceptual Contributions and Theoretical Linkages

The thesis also makes several conceptual contributions and theoretical linkages, primarily in relation to the interaction between the 'micro' level of lived experiences and the 'macro' level of social and health care system characteristics. This was done through addressing, in detail, the six research questions outlined above. The first was to explore the subjective meanings and experiences of dementia for respondents. By applying an IPA approach, I assumed that respondents sought to interpret their experiences in a form that was understandable for them (Brocki and Wearden, 2006: 88). This thesis yielded evidence to back up this assumption. Social constructionism and Sabat's (2002) concept of 'Selfhood' as outlined in Chapter Three (section 3.8) can provide an explanation to the meanings respondents placed on their experiences as a result of having dementia; namely maintaining a sense of their own identity or 'Selfhood' (Sabat, 2002). Respondents often attempted to normalise symptoms in the context of natural ageing, comparing themselves to others so they would not perceive themselves as different. It can be argued that these were also strategies to respond to the stigma of dementia. Some men and women in the study used expressions such as shame, feeling like a twit, and being embarrassed when describing aspects of their life relating to memory loss. Other strategies to sustain Selfhood occurred when for example, in a search for an understanding of symptoms, they sometimes saw themselves

as at fault, a consequence of laziness or inattention. This resulted in some respondents blaming themselves for the changes that adversely affected their lives and the lives of people close to them, and feelings of guilt sometimes ensued.

The second research question examined the social implications of having dementia. Findings showed that respondents were sometimes withdrawing from social interaction as a result of the biological effects of dementia (communication difficulties, forgetfulness), for psychosocial reasons (stigma and being treated differently) and due to physical restrictions (transport problems and mobility difficulties). It can be argued that withdrawal was a coping mechanism and another strategy through which respondents tried to maintain their identity as they did not want others to recognise changes in their cognition or memory. Despite this withdrawing most respondents remained socially engaged to varying degrees and enjoyed a range of activities from gardening to volunteering. An interesting core finding is the extent to which families helped to maintain this social engagement and in many cases were the predominant social network for respondents. However, friendship networks were extremely important and care-partners reported respondents were often 'at their best' when around close friends. Friendship networks also challenged the stigma associated with dementia, particularly when friends and peers treated the person living with dementia as they always had. This helped to maintain the person's identity within the peer group which also promoted belonging. This generally occurred when an Open Awareness Context (Hutchinson Leger-Krall and Skodol Wilson, 1997) existed. This occurs within social interactions when the person's dementia is openly discussed and accepted.

Findings established that respondents struggled to maintain a sense of their own identity but did not seek a 'collective self confidence' (Barton, 1993: 245) or a 'shared social identity' (Clare, Rowlands and Quin, 2008: 23) that comes from being part of a 'social group', in this case people living with dementia. Based on findings from this thesis, the majority of respondents were not cognisant or availing of their

rights, an integral aspect of the citizenship model. Nearly all respondents were managing well on a day-to-day basis, often drawing on humour and other practical coping mechanisms. However, the long-term management of dementia was not generally considered. Not all respondents were aware of their diagnosis and therefore did not know that they now had admittance to a new 'social group' as someone with dementia and as a result did not seek the company of other people in a similar situation, i.e. people who has been diagnosed or were experiencing the symptoms of dementia. Others did not know their prognosis and therefore in the main hoped to maintain the status quo or 'life as usual'. When peer support or engagement with other people who had memory loss was mooted by me during interviews, the majority of respondents did not wish for this (it should be noted that a small number did, but they expressed this in relation to a desire for more social engagement generally).

Findings which relate to the research question on the current service provision for people living with dementia in Ireland show that, despite huge advancement in understandings of dementia, the medical model still dominates, which also hinders citizenship. Dementia is still seen and treated primarily as a progressive and pathological degeneration of the brain and the body, leaving little space or attention to the *person* (Davis, 2004: 369). This is exacerbated by the fact that community-based social care is not legislated for, whereas health and nursing care (hospitals and nursing homes and public health nursing) are under particular legislation acts. The dominance of the medical model meant respondents were low services users, due to (i) the type of system that exists in Ireland; (ii) their low expectations for interventions; (iii) the lack of incentive and currency needed to engage with services (absence of physical ill-health); and (iv) relationship with service providers.

In relation to the fourth research question (accessing services), the data indicated that respondents and care-partners often waited until a critical incident occurred or until physical health deteriorated

before seeking formal interventions. The small number of respondents (N=6) who received a diagnosis and the clinical setting in which it occurred confirms the medical nature of service provision as little or no cognisance of people's social, psychological or emotional needs was taken. Innes (2002: 494) states that "If personhood is maintained, a sense of social confidence, worth, agency and hope will have been preserved for the person with dementia. In simple terms this means that a person with dementia will be confident to engage with others, will feel valued and accepted by others, be active and participate in activities that have personal meaning and will retain a sense purpose". This suggests that many respondents did not feel the benefits of the principles of Personhood. Referrals to services were largely dependent on the subjective beliefs of service providers as some respondents received referrals to services/interventions and others did not. This suggests that there are no natural or clear referral pathways for people living with dementia and few dementia-specific services are available for those in the early stages of dementia.

In relation to the policy implications of this investigation, the key finding is that the respondents were able to express themselves, to give insights into what it is like to have dementia and to highlight the deficits in the system. This constitutes compelling evidence of the potential of people with dementia to be closely and meaningfully involved in the evaluation and development of services which appropriately meet their needs. Findings have also highlighted the types of interventions people sought and emphasised the importance of activities that have meaning to their individual lives. The main aim of policy and practice should be to maintain and promote the quality of life of all stakeholders in the dementia process. These include those with dementia, their supporters (family, friends, and neighbours) and formal service providers. This requires a drastic change to the current system of health and social care.

9.4 Including People with Dementia in Research

One of the main aims of the research was that people living with dementia would be included successfully in the process without experiencing any undue distress. I feel that the interview technique used assisted in this as it allowed respondents to express themselves in ways that they felt comfortable with. A number of closed questions were asked in order to obtain basic background information and for the purpose of comparison with qualitative data. However, data was primarily based on a flexible semi-structured interview guide that allowed respondents to elaborate on issues that were of greatest concern for them, involving probing and the following of interesting avenues. The IPA approach was used for interpretation and analysis. Its use has been advocated as a method in examining the experience of health and illness (Smith, 2004) and in recent years it has been applied successful in research on dementia (Clare, Rowlands and Quin, 2008; Harmon and Clare, 2006).

An important finding of this research, supported by the literature, is that respondents living with dementia had much to say about their experiences. This is extremely important in relation to user-consultation mentioned in Chapter Eight, section 8.7. Findings indicate that directly asking someone with dementia about their memory gives a different indication of the level of impairment or the level of their awareness than using a quantitative measure. One example was when a large number of respondents reported having an 'Okay' or good memory, but analysis of qualitative data revealed that this quantitative measure, the five-point Likert scale, was not entirely accurate in reporting the reality. However, the answers respondents gave could also have been reflective of the fact that they genuinely thought their memory was good, particularly if they equated "memory" with "long term memory". Adapting Likert scales by incorporating other measures to gather data could increase their usefulness in dementia research, for example using pictorial representations (as is the case in communicating with people who have aphasia (Connect, 2008) and later-stage dementia) and

prompts and probes. If we look at the intellectual disability research literature, (Hartley and MacLean, 2006), it has been shown that the use of pictorial representations and expanding on probing questions facilitates the unfolding of people's stories. The interaction of qualitative and quantitative measures and data should be further explored and calls for further reflection on how people living with dementia are engaged in research so we can obtain accurate, valid and reliable data on their experiences.

The approach used in this study where I met informally with people living with dementia (before official data collection through in-depth interviews commenced) worked well. Good practice in relation to including people living with dementia in research requires that a researcher should meet with participants on more than one occasion. It is a good idea to meet respondents and their families a couple of times before formal interviews begin. This builds rapport and ensures that they understand the nature of the research and more specifically what their involvement entails. These meetings also allowed me to establish optimum ways of approaching the respondents.

Taking a person-centred approach to research methods meant ensuring that respondents did not feel coerced into taking part. Therefore I had to carefully consider the caregiver/receiver relationship, as it can often be care-partners, spouses, and/or children who want or feel that they should take part in research. A person-centred approach recognised that the person with dementia was autonomous and had the right and the power to make this decision. It was important, too, that respondents did not feel burdened by participating or feel that by not taking part their access and receipt of services would be affected. For instance, as referrals to this study were made in a hospital setting, it was important that respondents did not feel that they had to take part as a consequence of attending the clinic.

Interviewing respondents twice went some way towards counteracting the influence of good and bad days that people living with dementia experience. If a respondent was not feeling up to the interview on the first day or they did not want or wish to talk about their dementia, often during the second visit they expressed themselves differently. This also occurred the other way around, where some respondents offered more insights on their experiences during the first visit than during the second.

I noted a number of strategies that elicited positive outcomes when engaging people living with dementia in the research process, namely: (i) taking a conversational and informal approach to interviewing: similar to differences in outcomes from quantitative and qualitative techniques, respondents disclosed more when they were approached in an informal manner and when there were fewer restrictions on what they could talk about. (ii) Using easily comprehensible language in printed materials and in the phrasing of questions was also helpful, as this made it easier for respondents to understand the aims of the research and what their inclusion would involve. While the language in printed material was easily comprehensible, it was in hindsight somewhat too wordy and over-explanatory. I think it is also important, when working and carrying out research with people with early-stage dementia to be aware of the cognitive skills that many retain. (iii) Conducting interviews in environments and surroundings that were familiar to the person with dementia. In all cases interviews took place in respondents' homes.

The methodological approach, IPA, presented a number of challenges. My own lack of experience of using this method was a limitation. This can explain the divergence between the interview tools initially developed (see Appendix C) and the very flexible application of the tool (see Appendix G). The amount of data the approach generated and the management of this were challenging. In retrospect I would have done this differently as analysis took an inordinate amount of time. For instance, a smaller number of respondents would have allowed for more interpretation of the data.

Further data analysis on a small number of respondent's transcripts would allow for fourth or fifth level interpretation of the raw data. Smith (2004) suggests that the IPA approach can be used very successfully focusing on one case. There is huge potential to do this across this rich data set. Future research on for example the same data set would allow for further analysis and interpretation of one particularly rich case.

Part of the IPA approach is also being reflexive. I had to ask myself what part did my role as researcher play in how respondents interacted with me and in the responses and stories they told during interviews; were respondents trying to please me or more generally were they trying to report a positive impression of their lived experiences (as is suggested by their responses to structured questions on the extent of their memory problem)? Erving Goffman put forward the idea that people are social actors; who try to control the conduct of others by communicating an impression which will cause the other person to act in a way that meets their wishes. In this way I inevitably had an effect on the outcomes of the research. Researchers need to be cognisant of this fact when designing their enquiry and interpreting the raw data.

9.5 Implications for Future Research

Findings from this thesis have a number of implications for further research.

9.5.1 The lived experience

Most studies on the lived experience of dementia tend to be qualitative in-depth pieces of research. The potential for expanding our knowledge on the lived experience of dementia is growing thanks to the increased number of original pieces of research (this being one) on the topic. While this research was the first of its kind in Ireland, further synthesises of these findings and findings on the lived experience from other international studies could build an accurate and representative picture of the lived experiences of dementia.

Comparing findings across studies also adds weight to the 'real' meaning when much of the research is based on phenomenological or grounded theory approaches which require interpretations of the data. Although strategies are implemented to counter researcher bias (e.g. reflexivity and epoche) I believe the researcher plays a role in the outcomes of qualitative research investigations not just in how they interact with research participants but also in how they analyse and interpret the data. Examining consistency of findings on the lived experience across a number of studies could help us to garner a fuller picture of what it is like to have dementia.

This study did not take a detailed look at issues surrounding gender, age and social situation and the possible role they would have played in the lived experience or indeed experiences of health and social care services. For example, Mrs Gannon was 62 years old, the youngest respondent in the study. Her consultation in the Outpatient's clinic was unusual and went against common practice as it is a service for people aged 65 years and over. More detailed consideration of gender, age and social situation would have added depth to the enquiry. This is an area for further research.

9.5.2 Dementia and empowerment

This chapter has also highlighted the need for greater user-consultation to develop policy and practice. Cheston, Bender and Byatt (2000: 478) state that the inclusion of people living with dementia in service evaluation often amounts to little more than tokenism and "arguably the voice of service users is all too often heard only so long as it confirms the perceptions of powerful people within the service. As such it can be seen as a means of confirming rather than challenging the status quo". Another element to these types of enquiries is that we look beyond the lived experience and study it in relation to broader contexts, as this thesis has done.

9.5.3 Formal services

Further exploration of psycho-social interventions that are helpful and acceptable for both the person living with dementia and their care-

partners is needed. Part of this is examining relationship-centred approaches to coping with dementia. Findings showed that even in the most positive spousal relationships (Mr and Mrs Buckley) where their mutual support was evident, they did not talk about the fact that one of them had dementia. An intervention which supported both of them in their isolated coping, I feel, would have been positive.

Findings also show that the secondary care services offered through the Outpatient clinic had primarily a monitoring role. Mr Murphy's experience of receiving a diagnosis in this setting was upsetting and frustrating for him. As already stated there was little opportunity for him to ask questions and there was no provision made for an automatic and timely follow-up. It would also be interesting to garner the experiences of frontline service providers, such as outpatient staff, on their attitudes to dementia, and what they perceive their role to be in the provision of care and information.

3.5.4 Relationship with others

A key finding from the thesis was that a number of respondents felt guilty about the effect of dementia on their loved ones, in many cases stating that they did not want to be a burden. Further research looking at issues of guilt and the presentation of a positive front is needed, both in the context of close relationships (such as between spouses) and within broader, less intimate social networks. Findings from this research also suggest that in cases where there was a good relationship between the person with dementia and his or her care-partner, the person with dementia seemed to have a more positive experience and to cope better with the illness. Further research and investigation is required regarding the effect of relationship quality on the experience of dementia.

Findings from Chapter Six show that there is evidence that at least some, and possibly most, people do have the potential, ability and willingness to forge new friendships after the onset of dementia. A more detailed study of how these relationships developed once

dementia has been diagnosed would make for a fascinating new foray in dementia research.

9.5.5 Stigma and Ageism

In Chapter Eight one of the policy experts stated that dementia-specific policy and planning does not happen in a vacuum, but occurs in a societal and politico-economic context. The stigma of dementia is a common theme in dementia research and had an effect also on respondents in this study. Based on the findings from this thesis three further approaches to research on stigma and dementia in the Irish context are called for, namely: (i) investigating public perceptions of dementia; (ii) representations of dementia in the media, and (iii) stigma in social and health services and its effect on the use of services.

Respondents living with dementia and their care-partners in many cases expressed an expectation that frailty and deterioration was a normal part of the ageing process. This often affected their search for a diagnosis as early symptoms of dementia were viewed and treated as normal aspects of ageing. Respondents' and care-partners' negative views of old age are at least in part reflective of the widespread ageist belief in our society that quality of life is lower in older age. Low expectations of old age I think warrants further investigation as it has implications for the search for early diagnosis and subsequent interventions.

9.5.6 Research methods

The use of Likert scales in this thesis and response comparison with qualitative data added to our knowledge, especially on issues pertaining to awareness. In terms of future methods used in dementia research there is potential for them to be broader and more inclusive, encompassing people living with dementia in all stages of the process. Participatory and action research where people living with dementia are actively involved in an earlier stage in the research design and throughout the research process is also needed. People

living with dementia retain many abilities and their potential to take a more active role in research deserves further investigation.

9.6 Concluding Reflections

This study presented a descriptive and interpretive account of the experiences of people living with early-stage dementia and considered the wider implications of this. It can be argued, based on the findings, that people living with dementia in Ireland are denied full citizenship and opportunities to become part of 'a collective'. This is one of the reasons why the existing system and model of health and social care for people with dementia have not been challenged. The current challenge for people with dementia in Ireland is to sustain the 'self' when negative connotations of dementia prevail and rights to formal supports as basic as information about dementia are weak. In this context, this thesis has highlighted the crucial, sustaining role of families and other informal supports. While these informal sources of care and support will doubtless continue to be of central importance in the lives of people with dementia in the future, they will not be sufficient or available to everyone. Hence, it is imperative that both services and supports which work in tandem with families and, where necessary, in the place of families, are developed in Ireland.

There are enormous benefits to including people living with dementia in research. I feel it was a privilege to be invited into the homes of respondents and their care-partners. People spoke openly with me about their experiences. In conducting the fieldwork for this thesis, I did not know what to expect and the people I interviewed surprised me during each encounter, more specifically with their levels of insight, with the original and often imaginative ways they coped with the illness and the great deal of compassion they had for those around them. I would like to conclude by highlighting the need for further meaningful consultation with people living with dementia: as this thesis has shown, such consultation and involvement in research are clearly possible, and yield considerable dividends.

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APPENDIX A CONSENT FORM

Consent forms

Please circle yes or no for each question

Did you read the project information sheet?	**Yes**	**No**
Have you had the opportunity to ask questions?	**Yes**	**No**
Do you have any remaining questions?	**Yes**	**No**
Do you feel you know enough about the project now to participate in it?	**Yes**	**No**
Do you realise that becoming involved in this project will not effect your health care entitlements now or in the future?	**Yes**	**No**
Do you know that this project is an independent study being carried out by a Trinity College student as part of her postgraduate research?	**Yes**	**No**
Do you know that your name will not be associated with anything you say during this interview, it is confidential?	**Yes**	**No**
Do you know that you can refuse to answer any questions and stop the interview at any stage?	**Yes**	**No**
Do you know that you can drop out of the project at any stage?	**Yes**	**No**

"I consent to take part in this project"

Signed respondent:.....
Date:
Family member:.....
Date:
Witness researcher:.....
Date:

APPENDIX B RESPONDENT INFORMATION SHEET



Information on Impaired Memory Study 2006/2007

What is this research about?

This study examines the health, social, and support needs of a sample of community-dwelling people with memory problems. It focuses on quality of life and how this can be promoted and maintained. Helping to develop services that encourage social participation.

Rarely are people with memory problems asked to evaluate or direct policy and service development. This study differs from other research by including people with memory problems in the research process.

What will you have to do?

If you decide to become involved in this study you will be required to take part in;

(i) one face-to-face interview lasting approximately one hour and

(ii) a further twenty minute face-to-face interview carried out a few days after the first interview.

The care-partner/family member will be required to take part in;

(i) a face-to-face interview lasting approximately twenty minutes during the researcher's first visit.

If possible, interviews will take place in the persons own home or at another more convenient location. Topics that will be addressed during these interviews include;

- experiences of health services;
- living with a memory problem;
- current and future health and social needs

Names will not be associated with any information given. **Confidentiality is assured** at all times. You can choose to drop out or discontinue with the study at any time. If you do decide to take part you will be required to sign a consent form before the beginning of the first interview.

About the researcher

My name is Emer Begley. I am currently studying in Trinity College Dublin for a PhD in Social Studies. I am an independent researcher funded under the Trinity Social Policy and Ageing Studentship but I am acting in conjunction with -------- hospital's Age Related Health Care Clinic. If you have any questions or queries about this research or the researcher please contact Dr. Virpi Timonen (Trinity College), who is supervising this study on 01 ---------- or Dr. -------- -------- at --------- Hospital.

APPENDIX C RESPONDENT TO INTERVIEW SCHEDULE

Respondent Interview Schedule

Respondent code: _____
Date of interview: _____
Time duration of interview: _____
Place of interview: _____

Screening question: Have you recently experienced a life changing event? (For example a death or serious illness of some-one close to you) (Katsuna, 2005)_____
_____

Section 1: Background/demographic data

General question – **Can you tell me about yourself?**

1. Male/Female

2. When were you born? _____

3. Where were you born? _____

4. How long have you been living in this house?_____

5. Have you ever worked in paid employment? Yes/No

6. What are you working at/what did you work at? _____

7. *(If not in paid employment)* Which one of the following pensions, if any, do you receive?
   State non-contributory pension
   State contributory pension
   Other private or employment related pension
   Other _____

8. Have you ever been married? Yes/No
(Prompt here about marital status)

9. Do you have any children? Yes/No
If yes, how many? _____
How often would you see them? _____

10. Who do you live with at the moment? _____

Section 2: Memory Problem

General question – **Do you have a memory problem? Can you tell me about this?**

1. Do you regularly forget things? Yes/No

2. What kind of things do you forget? _____

3. How does your memory problem affect your mood? _____

4. When did you first notice you had a memory problem? _____
What happened? _____
How did you feel at the time? _____

5. Did you talk to anyone about it at the time? Yes/No
If yes, what was your experience of this? (who did you talk to, what did you talk about, how did you find this?) _____
If no, why not? _____

6. Since you developed a memory problem do you think people still treat you differently? Discuss _____
How? _____

7. Do you take any tablets to help you with your memory? Yes/No
If yes, what? _____

8. Do these memory tablets result in you experiencing any discomfort or side effects? Yes/No

9. Do you find your memory problem frustrating? Yes/No
If yes, what tends to frustrate you most because of your memory problem? _____

10. How would you rate your memory problem?
Mild (not that bad) Moderate (quite bad) Severe (very bad)

11. Do you think your memory problem will in time return to normal?
Yes/No
Discuss _____

Section 3: Diagnosis

General question – **Can you tell me about the time you first realised you had a memory problem?**

* If the person says they never received a formal diagnosis of a memory problem ask had they ever sought medical help/treatment about their memory problem?

1. Who told you that you had a memory problem?_____

2. What were you told? _____

3. Were you on your own when you were told? Yes/No
If no, who was with you? _____

4a. How did you react immediately once you were told?_____

4b. How did you react later? _____

5. Did you tell anyone at the time about your memory problem?
Yes/No
Discuss _____

6. Who have you told since about your memory problem? ___

7. Who do you think should tell those affected that they have a memory loss (i.e. family, GP, PHN etc)? _____

8. Do you think a family member should be present when receiving the news? Yes/No
Why? _____

9. Where is the best place to be told a diagnosis (for example own home, hospital or doctors surgery)? _____

10. Did *person who gave diagnosis* talk to you about your diagnosis? _____

11. Did you feel you were involved in any decisions discussed or made surrounding your diagnosis? Discuss _____

12. Did you receive enough information about your memory problem? _____

If no, what kind of information would you have liked (prompt technical information on physical/cognitive aspects of the illness; what to expect from assessments; causes of memory problems; practical information about services and benefits and advice on coping[1])? _____

If yes, what type of information did you receive?_____

Who gave you this information?_____

Was there any other information about memory problems you would have liked but you did not receive? _____

13. Do you think you should have been given advice or support after receiving a diagnosis of a memory problem? Yes/No

Discuss _____

14. *(Ask only if the respondent did not discuss diagnosis with a professional)* Do you think you would have benefited from discussions with a professional (like a social worker, doctor etc) after you received your diagnosis? Yes/No

Section 4: Scales

Clinical CDR Rating Scale

Preference scale (Sansone et al, 1998)
(Examines consistency of answers, this will be asked at two different time periods over one week)

[1] Keady, J. & Gilliard, J. (1998).

1. Do you like to watch television? Yes/No

2. Do you prefer winter or summer? Winter/Summer

3. Which of these colours do you like the best Yellow/Green/Red

4. Which of these three ways do you prefer to have your eggs cooked? Scrambled/boiled/fried/don't eat eggs

Section 5: Subjective Experience

General question- **Can you tell me what it's like having a memory problem?**

1. What is life like for you managing with a memory problem? __
_____

2. Has receiving a diagnosis of a memory problem affected how you see yourself? Discuss _____
_____

3. Has it effect how you get on with others? _____
_____

4. Do you talk openly about your memory problem? _____
_____

5. How would you rate your social life before you had a memory problem?
Very bad bad neither good not bad good very good

6a. How would you rate your social life now?
Very bad bad neither good nor bad good very good
6b. What has changed *(if anything)*?_____
6c. Have any of the changes been a direct result of your memory problem? _____

7. How would you rate your self-esteem/confidence before you had a memory problem?
Very low low neither low nor high high very high

8a. How would you rate your self-esteem/confidence now?
Very low low neither low nor high high very high
8b. What has changed *(if anything)*? _____
8c. Have any of the changes been a direct result of your memory problem? _____

9. How would you rate your quality of life before you had a memory problem?
Very bad bad neither bad nor good good very good

10. How would you rate your quality of life now?
Very bad bad neither bad nor good good very good

What has changed *(if anything)*? _____

Have any of the changes been a direct result of your memory problem? _____

11. What factors are most important to your quality of life?_____
_____

Section 6: Activities of daily living/Independence

General question – **Can you tell me about your life from day-to-day?**

1. Do you have a daily routine that helps you with your memory problem? Yes/No
Discuss _____

2. Have you developed any techniques that to help support your memory? (give examples is necessary – writing days of week on paper etc.) Is there anything you do that helps?
Discuss _____

3. Which if any of the following tasks do you need help with? *(These will be read out to the respondent)*
How often would you need help with them?

Personal tasks	Never	Daily	Weekly	Monthly	<once a month
Toileting					
Dressing					
Washing					

Household tasks
- Cooking
- Cleaning
- Shopping

Financial tasks
- Paying bills
- Managing pension

Other _____
Who usually helps you with these? _____

4. Do you regularly receive any of the following services?
Since you started having a memory problem how often would you see them?

	Never	Daily	Weekly	Monthly	<once a month
Public Health Nurse					
Community Psychiatry					
Home help					
Meals on wheels					
General Practitioner					
Psychiatrist					
Psychologist					
Occupational Therapist					
Physiotherapist					
Other _____					

If yes, to any of the above, how were your experiences of this/these services? _____
If no, why have they not used the above service_____

5. Do you attend a day centre? Yes/No
- If yes, do you enjoy time there? _____
- If no, would you like to go to one? Yes/No

6. *(Only ask if the respondent talks openly about their memory problem)* Did you ever contact the Alzheimer's Society? Yes/No
- If yes, why? *(If no go to question 7)* _____
- If yes, did you find them helpful? _____

7. Are you a member of any clubs/groups? Yes/No
- If yes, what? _____
- Does this club/group you attend meet often? _____
- What does involvement in this group mean to you? _____

8. Do you drive a car now? Yes/No
- If no, did you ever drive a car? Yes/No
- If yes, why have you stopped driving? _____
- How has this affected you? _____

9. Are there any activities that you are not 'allowed' do now because of your memory problem? Discuss _____
How does this make you feel? _____
Who told you that you couldn't do these activities anymore?
_____

10. Are there any other activities you feel you cannot do now because of your memory problem that you once enjoyed doing? Discuss_____

11. What is the most significant problem you face on a regular basis because of your memory problem? _____
_____

12. What if any are your future fears because of your memory problem? _____

Section 7: Support Services/Needs

General question – **Can you tell me about what you need or would like to help you on a daily/weekly basis?**

1. What kind of State services do you think should be available to you and people with memory problems? _____

2. Would you like to meet up/talk with other people that are in a similar situation to yourself? (Either support groups for people with a memory problem or couple's support groups if married or in long-term relationship) Yes/No
_____

3. Has your attitude towards memory loss changed since you yourself developed the problem? Discuss _____

4. Is there anything else you would like to add before we finish?
_____

5. Did you find participation in this research acceptable?

Do you have any suggestions for how the research could be carried out differently?

6. Would you be willing to take part in a follow-up interview in a few years time? Yes/No

Thank you very much for your time, you have been extremely helpful.

Field notes and comments after interview:

APPENDIX D RESPONDENT T1 INTERVIEW SCHEDULE

These were developed after T0 and were specific to each individual respondent. This following T1 interview was developed for Mrs Beattie after T0.

Respondent T1 Interview Schedule

Respondent code: _____
Date of interview: _____
Time duration of interview: _____
Place of interview: _____

1. When your husband was alive what did he work at? ___

2. You mentioned you have a history of depression can you tell me a little bit about that? _____

3. Can you tell me more about the relationship you have with your daughters? _____

4. You mentioned as well how good the local pharmacist is, and how your neighbours look out for each how important is the local community to you? _____

5. Do you think you would have benefited from discussions with a professional, like a doctor, counsellor or social worker, after you received a diagnosis of dementia? _____

6. Preference scale
(i) Do you like to watch television? Yes/No
(ii) Do you prefer winter or summer? Winter/Summer
(iii) Which of these colours do you like the best?
Yellow, red or green?
(iv) Which of these ways do you like your eggs to be cooked?
Scrambled, boiled or fried

7. Would you say you are a sociable person? _____
Do you have close friends? _____

8. You mentioned you feel afraid sometimes, can you tell me about that? _____
   Does this happen often? _____
   Does it happen more often now than before? ___
   Has this changed since you were diagnosed with dementia? _____

9. Can you describe for me a typical day for you? _____

10. Do you have a daily routine? _____

11. Where do you do the guiding for the blind people? _____

12. You mentioned that you know when you shouldn't drive can you explain this feeling to me? _____

13. Can you tell me about when the Public Health Nurse called o you? _____

14a. How would you rate your quality of life? _____
14b. Has this changed since you developed dementia? ____

15. Are there any activities that you would like to do that you are unable to do at the moment? _____

16. What type of State services do you think should be made available to you and people with dementia in Ireland? _____
_____

17. Has your opinion of dementia changed since you were diagnosed with the illness? _____
_____

Thank you again for giving up your time to talk to me, I greatly appreciate it.

APPENDIX E CARE-PARTNER INTERVIEW SCHEDULE

Care-Partner Interview Schedule

Respondent code *(coded 001, 002 etc)*:
Date of interview: _____
Time duration of interview: _____
Place of interview: _____

Section 1: Background/Demographic data

Carer/Family member:

1. Male/Female

2. What is your date of birth? _____

3. What is your relationship to *name*? _____

4a. Are you in paid employment? Yes/No
4b: If no were you ever in paid employment? Yes/No
What did/do you work as? _____
4c. If yes, on average how many hours a week do you work?

5. Would you say you are *name's* carer? Yes/No
If yes, would see yourself as *name's* primary carer? Yes/No
How long have you been in the role of carer? _____
What does caring mean for you? _____

6. Do you receive any financial support for caring for *name*?
Yes/No
Carers Allowance
Carers Benefit
On Carers leave
If yes, do you think it is adequate? Yes/No

Respondent: _____

7. When was name born? _____

8. Where was *name* born? _____

9. How long has *name* been living in this house? _____

10. Has *name* ever worked in paid employment? Yes/No

11. What is *name* working at/what did *name* work at? _____

12. *(If not in paid employment)* Which one of the following *(if any)* pension does *name* receive?

State non-contributory pension
State contributory pension
Private or employment related pension
Other _____

13. Has *name* ever been married? Yes/No

14. Does *name* have any children? Yes/No
If yes, how many? _____
How often would *name* see their children? _____

15. Who does *name* live with at the moment? _____

16. If you do not live with *name*, how far away do you live from him/her? _____

17. In your opinion does *name* have a memory problem? Yes/No

18. What kind of things do they forget? _____
_____

(Give examples if they have difficulty answering – mislaying things, forgetting names, places, space disorientation, short-term memory problems, long-term memory problems)

19. Has *name* had any other serious, chronic, or long-term illness?
_____

If yes, what treatment are they receiving for this? _____
_____

20. Is *name* taking any prescribed medication for their memory problem? Yes/No
If yes, list medications _____
If yes, what changes, if any, have you seen in *name* since he/she went on them? _____

Section 2: Diagnosis

1. When did you first notice that *name* had a memory problem? _____

2. How was their memory affected? _____

3. What did you do about this? _____

4. In your opinion, when do you think *name* became aware that they had a memory problem? _____

5. *(Ask only if person with memory problem is aware of their diagnosis)* Did *name's* behaviour change once they became aware that something was wrong? _____

6. When did *name* receive a formal diagnosis of memory problem/memory problem? _____

7. Please describe the process *name* went through around their diagnosis (for example assessment, referral etc.)? _____

8. In your opinion how did *name* cope with this diagnosis? _____

9. Do you think *name's* memory problem was diagnosed in an appropriate manner? Yes/No
Discuss _____

10. How did the diagnosis of the memory problem affect you? _
_____

11. How is your and *name's relationship* with your GP? _____

12. In your opinion how helpful was the GP *(if they met with them)* to *name* in relation to their memory problem? _____
What did he/she do? _____

13. In your opinion how helpful was the PHN *(if they met one)* to *name*? _____
What did he/she do? _____

14. Was there anyone else who gave *name* a lot of support? Yes/No
Who was it and what did that person do? _____

15. Did *name* receive any kind of an assessment of need after they were diagnosed with memory problem? Yes/No
If yes, by whom and when did this happen in relation to diagnosis? _____
If no, did you request this? Yes/No
Do you think this is important? Yes/No
Discuss _____

Section 3: Caring

1. Which if any of the following tasks do you assist *name* with?

Personal tasks	Never	Daily	Weekly	Monthly	<once a month
Toileting					
Dressing					
Washing					
Household tasks					
Cooking					
Cleaning					
Shopping					
Financial tasks					
Paying bills					
Managing					
Pension					

Other _____

2. Has the nature and amount of time you spend caring changed overtime? Yes/No
If yes, discuss _____

3. Does anyone else help you provide informal care (family, friends, or neighbours) for *name?* Yes/No

If yes, who, and how many hours a week on average would they provide care? _____

4. Does *name* receive any of the following services?

	Never	Daily	Weekly	Monthly	<once a month
Public Health Nurse					
Community Psychiatric Nurse					
Home help					
Meals on wheels					
General Practitioner					
Psychiatrist					
Psychologist					
Occupational Therapist					
Physiotherapist					
Other _____					

5. Does *name* attend a day centre? Yes/No

If yes, how often per week and who runs the day centre *(is it memory problem specific)?* _____

In your opinion do you think that *name* finds it beneficial?

_____

Discuss _____

6a. Did you ever contact the Alzheimer's Society? Yes/No

If yes, what is your opinion of their services? _____

6b. Did you ever contact the Carers Association? Yes/No

If yes, what is your opinion of their services? _____

7. Do you think current community based services are adequate for you both? Yes/No

Discuss. _____

8. Do you think your care input is manageable? Yes/No

Discuss _____

9 What do you think could be provided for *name* to make both your lives easier? _____

10. Can you tell me about the financial cost of care to you personally? _____

11. Who do you think is responsible for providing care to older people and people with memory problems in Ireland? _____

12. Who do you think is responsible for paying for this care?

13. How much do you think the State should pay Carers on a weekly basis, if anything? _____

15. Do you think you have sufficient information about memory problems to equip you in your caring role? Discuss _____

Section 4: Coping

1. Do you think a counselling service, for either of you, after diagnosis would have been beneficial? _____

2. Do you think support groups for people with memory problems are a good idea? Discuss_____

3. In the period immediately following diagnosis did you receive any supports?
Professional and/or personal? Describe _____

4. How do you think *name* is coping with their memory problem now?
_____

5. How is *name's* mood? _____

6a. Is *name* sociable? Yes/No
6b. Is *name* active? Yes/No
How important is this, in your opinion? _____

7. Do you think any particular service could help *name* cope more effectively? _____

8. Since *name* was diagnosed with a memory problem, has your relationship changed? Yes/No
If so, how?_____

10. In your opinion has *name's* relationship with others (family and friends) changed? _____

Section 5: Carer Well-being

I would like to know how your general well being has been in the past few weeks. I will read a number of different statements to you and can you please let me know the response that best describes the way you have been feeling recently in relation to each of the statements asked.

	Never	Rarely	Sometimes	Frequently	Always
1. Do you ever feel you can no longer cope with the situation?					
2. Do you ever feel that you need a break?					
3. Do you ever get depressed by the situation?					
4. Has your own health suffered at all?					
5. Do you worry about accidents happening to name?					
6. Do you ever feel that there will be no end to the problem?					
7. Do you find it difficult to get away on holiday?					
8. How much has your social life been affected?					
9. How much has the household routine been upset?					
10. Is your sleep interrupted by name?					
11. Has your standard of living Been reduced?					
12. Do you ever feel embarrassed by name?					
13. Are you at all prevented from having visitors?					
14. Do you ever get cross and angry with *name*?					
15. Do you ever feel frustrated at					

times with *name*?

Comments/Notes/Observations
(observations regarding carer's compliance with responses etc.)
_____
_____
_____

1. How would you rate your own health?
Excellent Good OK Bad Very Bad

2. How would you rate your quality of life?
Excellent Good OK Bad Very Bad

3. How would you rate *name's* quality of life?
Excellent Good OK Bad Very Bad

4. Did you find participation in this research acceptable?

5. Do you have any suggestions for how the research could be carried out differently?

Thank you very much for you assistance. Is there anything further you would to add before we finish the interview? _____
_____

Researcher fieldnotes, observations and comments:

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

APPENDIX F POLICY EXPERT INTERVIEW SCHEDULE

Interview schedules were developed individually for each policy maker, with some questions specifically relating to their role. Therefore schedules slighted differed across the policy adviser sample. The following is an interview schedule developed for interviewing a representative from the Health Service Executive.

Interview with Policy Adviser

Name: _____
Organisation: HSE, Services for Older People
Date: 01/06/07
Duration of interview: _____

Section 1: Role in Policy/Service Development

1. What is your current occupation? _____

2. Can you tell me about the structure of older people's services within the HSE? _____

3. What role have you had to date in the development of dementia policy and/or practice? _____

Section 2: Policy Issues

1. What do you perceive are the main policy issues relating to older people's health and social care in Ireland? _____

2. What do you perceive are the main policy issues relating to dementia health and social care in Ireland? _____

3. The main policy report on dementia in Ireland was An Action Plan for Dementia, published by the National Council on Ageing and Older People in 1999, since then do you think any new policy issues have emerged in relation to dementia health and social care? _____

4. An Action Plan produced a list of 33 recommendations, very few of which have been implemented, why do you think dementia is not a high priority in health and social care policy? _____

5. The APD recommends an exploration of moving to a social insurance system, do you think this is a viable option for long-term dementia care? _____
If yes, how would you perceive its implementation? _____

6. Do you think dementia services should be integrated within community care systems or provided separately? _____

7. Do you think a national database should be established to record information on the users of dementia services in Ireland (similar to the HRB's National Intellectual Disability Database (NIDD)_____

8. Do you think the needs of people with dementia and their family supporters are being met? _____
If not, why do you think this is the case - financial; structural; resource issues; no understanding of need? _____

9. What do you perceive are the limitations of current policy on ageing and older people? _____

Section 3: Health & Social Care in the Community

1. What is the community intervention team? Do the rehabilitation team in the community service older people?
(above questions references to other HSE representative interview)

2. What do **you** think are the most important issues for people with dementia living in the community (specifically those in the early-stages of the illness)? _____

3. In what way do you think the needs of people with dementia are being met within current community based services (in your opinion what is working)? Discuss: _____

4. How do you think people with dementia could be better supported in the community? _____

5. Do you think current entitlements for people with dementia are adequate? _____

6. Do you think current entitlements for their carers are adequate (e.g. carers allowance, respite care grant etc)? _____

7. What are your thoughts on the co-ordination of care in the community?_____

8. Who do you think should be responsible for the management of dementia services, voluntary v's state provided care; families; specialist care v' geriatric care; community care; publicly funded private care? _____

9. Do you think there is a clear/transparent system for overseeing the development of services for people with dementia at a local level? Or at a national level? _____

Section 4: Future of dementia care in Ireland

1. What do you think is the future for dementia care services e.g. tailored care packages; care/case management; advocacy; needs assessment; home sitting services; personal assistant care models; individual care plans? _____

2. Social inclusion was a key theme that emerged when talking with respondents in the first phase of my study e.g. loss of independence, impaired ability to remain active. How do you think this should be addressed? _____

3. What do you think are the main challenges for policy makers in providing community care services for people with dementia in the future? _____

4. The 2007 Alzheimer's Society Ireland's Dementia Manifesto calls for dementia to be made a national priority, what are your thoughts on this? _____

Is there anyone you think would be useful for me to talk to about dementia policy and practice?

Any other comments _____

Thank you again for your time

APPENDIX G T0 Interview with Mrs Beattie

Conducted on: 21st of February 2006
Conducted in: the respondent's home
Interview length: 1 hour and 32 minutes
I = interview
R = Respondent

We chat for a little while before the tape is turned on and data is more formally collected.

I: Can you tell me a little bit about yourself Mrs Beattie?
R: Emm
I: What year were you born? When were you born?
R: Born, I was born the 29th of March, 1938.
I: Where about's were you born? Are you from Dublin?
R: Wicklow.
I: Wicklow and have you been living in this house here, for a long-time.
R: Oh yeah.
I: The whole time you have been in Dublin?
R: No, no not the whole time I was in Dublin but here, now for it must be. I'm not positive but here in this house I know that, we didn't come here when these houses were brand new.
I: That might be twenty years or over twenty years?
R: I'd say over, yeah.
I: OK and did you ever work in paid employment?
R: Yep.
I: What did you work at?
R: Well, do you mean when I was young?
I: Yes.
R: I worked for my aunt who had her own business, a shop.
I: And did you work when you were married?
R: Oh yes, after I got married I worked again in part-time work in a ------ down at -------- and shop work.
I: Did you like it?
R: Yes, and I do often think of the people and then after that finished I worked for the driving school.
I: Were you a driving instructor?
R: No.
I: Or secretarial?
R: Yeah.
I: And are you receiving a pension at the moment?
R: Just from my husband's work.
I: So you have been married?
R: Oh yes.
I: And do you have any children?
R: Two girls.
I: Two girls, do you see them often?
R: One girl, because the other girl has cancer and she lives in ------ actually but the other girl that's where I'm going emm, lives up wait now..... Gosh I forget now. I know how to go.
I: Do you talk to them often on the telephone?

R: Oh yeah, yeah.
I: Do you live in the house here by yourself?
R: Yeah.
I: Would you have a good relationship with your daughters?
R: Yeah.
I: Your close... and one of them is sick?
R: Yeah ------- but she's doing well. She's not to go back for, December gone until June. That's very good.
I: Do you have a memory problem yourself?
R: Oh yeah.
I: Can you tell me a little bit about it?
R: Yeah that's very frightening.
I: Is it?
R: Very, very frightening. And eh very confusing even when I'm making... Oh I have a scone if you'd like one?
I: No I'm grand thanks.
R: I do try and make, for to give some to my friends that are blind especially and I've everything ready out in front of me and I really want to do it and then when I'm working and I'm doing that and when the eggs I'm breaking the shell to mix with the milk I put, this is only an instance now, I'd put, I'd have the waste bin here, and I'd put the shell part of the egg into the flour and put the, what I should be putting into the scones into the waste. And then of course the oven, you do turn it on when you start to prepare, and would, most times, now most times I wouldn't have turned it on.
I: OK, have you ever left the oven on and forgotten to turn it off?
R: Yeah, emm, I have.
I: You said that its frightening?
R: Yeah, it's, of course it's frightening then one day when I got the pension and it was, I didn't go near the roundabout now but I just parked it in off, by where you go on the bicycles on ------ road and I came back around form the Post Office again, I was coming home. And the car behind me was putting on, you know the big lights in the car, the blue. And I didn't understand, I thought genie it must be somebody knows me but kept and then a little sound of the horn and then I said I'll have to pull in, the wheels must be coming off the car or something. But I put my two purses up on top of the car and that's what the person was and I pulled in and that car passed out and the next car kept going and the two of them were on the ground.
I: You were lucky.
R: Terribly things, and it's terribly in your own house in the day and night you have to have the doors locked but like, but I was always leaving the front door open, very much. And emmm, my neighbour, very good this side and this side and all the neighbours, like we all help each other if there's something you know that has to be like something that you can help. And my neighbour ------ said I'll kill ya if you don't stop leaving the door open. Well anyone, you wouldn't have to be retired guard, you could be killed in your house and we won't even know it. Because it's a different world what we're living in. And em...
I: Would you ever forget people's names or faces?
R: Yeah, all the time. All the time. Well then maybe there might be a few, I have been trying to think actually for four days of the name of a friend of mine in the driving school. Actually though I had to leave

when -------'s cancer was bad you know, because even though I had been there thirteen years my boss at the driving school wouldn't give me lets say temporary leave. And I have, it's amazing now you should ask me that because I've been thinking and thinking of, she was a lady instructor and I was saying to myself would, actually she didn't work for the company I worked for she was working on her own. But if my boss was stuck you know, he would inform her. And I was saying I'll have to ring up ----- my boss's wife and try and find out, because it keeps at you and at you.

I: Is it like when I forget something, you can't rest till you have it, and it's like it's on the tip of your tongue. Is it like that?

R: Yeah, and the phone, if I take an answer machine message from the phone, emm, Emer, if I do, it happens like at the very moment, gosh I don't know who that was. Or I, I can't remember who the message, who was speaking on the message. But you see I write down all the things, this is the memory calendar.

(Mrs Beattie takes down a calendar that hangs by the phone with all her appointments written on it)

Oh I learnt this down in the Occupational therapy.

I: You went to occupational therapy?

R: Oh I went for thirteen weeks up in ---------, day care. Day care centre yeah. And very nice and learned how to do the phone for the make different markers, with a line say for three numbers and then a line and so many and then the line, it helps to hold it in front of you like that rather than, because you would have to try maybe like seven times to do the number I wanted and they taught you that. And also, speech therapy because when I got not well in the beginning, I was mixing up say only for an instance if there were only four or five words in a little sentence I was saying the last word first and mixing it all up, that's the truth.

I: And they sorted that out for you?

R: Ah no, they helped me.

I: You sorted it?

R: Ah yeah, they helped me they couldn't sort that out when you have dementia, Alzheimer's. They couldn't but they helped me to cope, do you understand. And then I had a brain scan and emm, they're very nice, well I hadn't the brain scan in the day care centre I had it in the main hospital that you know.

I: Was it important going to the day centre in ------ for you?

R: I didn't really like going, no. But they used to collect ya and bring you back and you got your food and I have to show you what I nearly died trying to do this.

(Mrs Beattie takes out a clear plastic painted sheet which she painted during her time in the day centre in ------)

Oh my God I'll never forget it; I used to do it in between...

I: That's great.

R: Isn't it lovely though, I was just saying I'm going to get a little frame for it.

I: You should, and you know that would be lovely up on the window.

R: Yeah.

I: But you didn't really like it though?

R: No because it was like very frightening because there was people whose more ill a lot than me.

I: So, was it that you would have preferred it if it was all people experiencing the same kind of thing as you?
R: Ah no, I know what you mean, but no you see I like to help people, I would. I would , I suppose the fear of the unknown you know that's, that's...(pause).
I: Did you decide to stop going yourself?
R: No, no you're only allowed to go for so long. You go to the big hospital first and then Prof...(pause)
I: --------.
R: --------'s his team and all arranged it for to go to the occupational. Sure I had nineteen blood test done last year. Sure they most know everything by the bloods.
I: When did you first notice that you were starting to forget things?
R: It was speaking mixed up and writing, not last year the year before.
I: Did you do anything about it? Did you talk to anybody about it?
R: Oh I went to my own doctor. I didn't tell him for a good while, you know I thought maybe it would go away. But my friends were saying but Betty you'll have to tell because you'll have to. But then it was more the speech and the writing rather than the, rather than the memory. And they'd be laughing and all, and I'd be laughing you know we'd all laugh. But immediately my own Dr. -----referred me to... (pause)
I: --------.
R: Yeah.
I: OK. Did you're daughters notice?
R: Yeah.
I: So you were kind of hoping it would get better by itself?
R: Yes, yeah. I could have coped with saying things back ways. Once when I was receiving the Eucharist I said thank you very much goodnight. Instead of amen (both laugh).
I: Would you be religious then? Do you go to mass much?
R: Ah yeah, ah yes I bought that little book *(Mrs Beattie shows me a prayer book)* as well and I might read it. But you see I can't, I forget when I read, I can't not remember and I do be saying what's the use in, what is. Then maybe I remember as well, maybe before not this year but the one before. But I would say I'm going to listen to the news and it would be over and nothing.
I: Did it affect you mood, when all this was happening, did it get you down?
R: Well I have a chemical imbalance on that side of my brain. I would have a history of, I'd say of depression you know.
I: Do you think it has gotten any worse or any better recently?
R: No, the same. It varies, like you would have various feelings and different sometimes but most of the time you feel like you would like to cry you know that way. Or like you could cry very easily. Like I have to only keep saying don't think about the little children and the mammy.
I: That were killed last week?
R: That's somewhere up near my ----'s oh yeah. And like other things, realistic things.
I: When you went to eh doctor and he referred you onto ------ hospital. When did you get your diagnosis of dementia?

R: Oh that I got, it went on, they got the brain scan done in the big hospital, and I, I'd say last, it was only after the brain scan was done the doctor said that I'm , I'd say about last September.
I: OK. Did you tell anybody else about it, you're friends or?
R: Yeah, well they say yes I have that too. But they don't really. Like, like, as well in the car you would know the way to go definitely but you get a feeling that you don't know, that you're going wrong. Do you understand?
I: Doubt, is it doubt?
R: Yeah, you think really and truly. I had a really, really this happening to me when coming down from ---- my daughter, I'd seen the two signs to come on left, do you understand, for -------, but it's the truth, I was no that's not right, that couldn't be right and I went down Wexford road.
I: OK, emm, are you taking any tablets for your memory?
R: Wait till you see. I really upset, no I'm not upset 'cause it can't be helped. The doctor up in -------told me that there was three known, three, but drugs now in Ireland to help but I was put on aricip, only one little small tablet, very small. Well one, tablet, one tablet that's all I had to take each day for six weeks but then when it had to go, that was five, and then it could only go to ten milligrams. And I was got, that was arranged and then it was only eight days I was taking the increase and emm I had all sorts, feeling terribly sick and nearly being sick and the bowel so my doctor, my own Dr. -------- said because I had surgery on my bowel as well that he'd have to, he'd have to really know that it was the tablet rather than something else. It was then he put me on this *(Mrs Beattie shows me box of exelon)* as an alternative.
I: Exelon.
R: Yeah, by aricip is supposed the better of the... (pause)
I: You have to take it less often I think, aricept you take it once a day.
R: Yeah once, I take, do you see only the level it is?
I: 1.5.
R: And I was put on it as an alternative.
I: And how are you finding this one? Do you find it helps?
R: Well alternative but then after six weeks the same, it has to be six weeks to come work and then increase. And I know I tried the increase with this one after six weeks and I thought I was going to have to go back into hospital. I only took, you take one in the morning and one in the evening of that, but I only took one in the evening it so happened I had to go on the increase, and one in the morning. And I was just like this, all dizzy and then really, really eh, all the time, couldn't be sick and all this dry retching. So I phoned down to my pharmacy and before I didn't, it wasn't happening bad wanting to bad. And ------- said oh Betty don't be worrying it's the increase and that, because she had people that couldn't even take the lower. Is that, I thought, believing me I thought I was only take one in three, I thought it was very little that was sent up. Well anyway.
I: Would you say that your memory problem is good or bad, or someplace in the middle?
R: Oh severe.
I: Severe, OK. And do you think it has improved at all since you first were diagnosed?

R: Ehh, you see I forget the girls name, she was lovely. The occupational therapist and she said to me it's better if you don't write down when you're going to the shop but in here do it *(Mrs Beattie points to her head)*. Only try to do four things, say you have to think if say that you need bread, instead of writing down bread, ham, butter and you have to imagine that you are going to eat a lovely sandwich. And keep it in here *(points to head again)* when you go up to the shop then.
I: You know what to get.
R: Without depending on the paper.
I: Does that work for you?
R: No, well, a bit, sometimes but sometimes I have three things that I want, I have three of them and I haven't got one thing of what I really wanted do you know that way. Yeah.
I: When you got your diagnosis from the doctor, when they said it was Alzheimer's disease, were you by yourself when they told you or were your family with you?
R: Ah no, no because you were brought, like 'cause they collected you in the morning and emm, brought you back. Yeah.
I: When you were told how did it make you feel?
R: Eh...(long pause)
I: Were you glad to know what was wrong?
R: Oh I was glad that it wasn't, in the sense of having a brain scan that it wasn't a tumour, like cancer or something.
I: Were you concerned about that?
R: No, I wasn't worrying about it really, I wasn't but to choose between the two like you know.
I: And did the doctor tell you in an OK way, were you given time to ask questions and that?
R: Ah he was lovely, he was Chinese. Chinese, lovely. And eh, oh he told me, he did. Oh I never finished telling you what ----- did for me, she's so good.
I: Is she the occupational therapist?
R: No, the pharmacy, ------ --------, she won an award this year, before Christmas with three other people, an award for how kind she is. It's only down on ------ road but when, she said 'don't worry Betty', I'll go to bed, 'because you need to go to bed when you're dizzy and I'll come up at lunchtime'.
I: This was about the tablets?
R: Yeah. 'Put the key under the matt and emm don't worry about it'. But then I didn't, I was afraid to go to bed because ...
I: With the retching and stuff?
R: Oh yeah and I was afraid I'd choke or something. So I rang her back and she said 'oh don't go to bed sit in on the sofa and sit down on the sofa up high' and she came up. She's as good, she is really and she made toast and tea and she bought up for being sick, for feeling sick the little blue tablets and she made me then go to bed. I told her I didn't want to though, she said now 'Betty you need to go to sleep and I'll come up'. And she came up at six, she was. She's the best, as good, but she is Emer yeah.
I: What is your GP like, Dr. --------?
R: Ah, actually I had to go down to Dr. -------- yesterday because I had the most dreadful pain in my head. But even the pain, even to do that I couldn't *(Mrs Beattie places her hands on head)* I couldn't,

well I could, I could but the sore and emm, like for about seven days maybe before, when I wasn't going to the loo passing urine and I thought that it was a bit strange and emm, because as well I have the bowel. When I had the bowel operation and the doctor said if everything is alright you can go home in five days and I couldn't go to the toilet, I couldn't pass any water even though it was the bowel that was operated on and they didn't know. I was in the hospital nearly two months and they only let me home...

I: When was that?

R: About two years ago. They let me only home using the catheris.

I: Did you memory problem happen before or after the bowel? When did you notice it really?

R: Oh the memory was playing tricks with me.

I: Before that?

R: Yeah but you know something I was saying to myself, I hate going down and paying forty pounds you know. And I was saying I'll get the cranberry juice and keep drinking that, drink water. I'm great at drinking, you have to drink a lot with all the tablets and emm, anyway when I got this desperate thing. I was passing urine but there was something not right, up inside of me so I had to go down yesterday to the doctor.

I: You're not over seventy then?

R: No.

I: So you don't get the free medical card yet?

R: No. But Dr. -------- said you have to give a urine sample. And he can do it and he said very acute infection. And that's what, and I was shivering even with all these things on me. And I only heard when ------ was in hospital one time, they didn't think she would have ever lived.

I: Is this your daughter?

R: Yeah that has the cancer. But I thought you'd be roasting if you had a very, very, very serious infection. But you can be freezing, shivering, can't stop and that's the way I was.

I: Yesterday?

R: Yeah and my hands, and inside me as well. And Dr. ------ said as well that's it's acute infection. So I have to take these now as well as these, I'm like a walking chemist shop. And I have to leave them all out, but that's for the infection. And then I told him as well, when I was there. And these are for the pain, the I don't know what it is, if I told you I'd be telling lies whether it's osteoporosis, arthritis or something shocking but the little Chinese doctor got these x-rayed *(Mrs Beattie shows me her fingers)* see that's not a bit sore because it's gone like that, it isn't really I could press, but see that one, they x-rayed that and the little Chinese doctor said that's, he was really lovely, that banjacked and bangoed. But would you ever know that well that hurts me up here *(this refers to finger that causes pain all up the arm and into the shoulder)* and I told Dr. ------, he actually he's to ring me. I asked, I rang

(Mrs Beattie shows me the information documentation that came with her medication as she is worried that it might not be compatible with other medication she is taking. She is waiting to hear back from her doctor by telephone about this).

I've had everything. Somebody said to me do you have diabetes, I said no, not yet, not yet (laughs).

I: When the doctor told you, back to the Alzheimer's for a minute, when the doctor told you that it was Alzheimer's did you feel that he told you enough about it?
R: No he didn't tell me anything. He just said take those tablets and if they make you sick stop. That's all.
I: So who told you about it?
R: He told me. That's all he told me.
I: Did anybody tell you anything about it?
R: No.
I: Would you like more information about it.
R: I would, I really would. Honestly I really would, Emer.
I: Well, your going into ----- hospital tomorrow are you?
R: Isn't it there on that? *(Mrs Beattie points to calendar)*
I: I'll tell you now, Dr. ------ is tomorrow, 2.15.
R: Sometimes I don't know what I have written down on that. Oh God. I'm in ------ tomorrow.
I: Ask questions tomorrow if you want to ask questions about it. If you have anything, that's why they are there Mrs. Beattie. You're looking conf...
R: Yeah, well I might say if the arcip is the better one.
I: Exactly.
R: Would it be feasible if they could give me aricip with something that your wouldn't get sick. I might blow-up.
I: You'll take off.
(Both laugh)
I: So how do you know that the aricept is better, is it just your own..?
R: I'll tell you how I know. Will I tell you?
I: Yes please.
R: My friend B-----, she told me, she read on a daily paper but it was a patient in Britain that was on aricip and the same patient had a sister or a brother or something, this is now what, she put it somewhere she couldn't find it. But the doctor did say in the very beginning there are three drugs I don't know what the other one is, their names.
I: There's exelon, aricept and ... oh I can't remember.
R: No I don't know either. I only know then because I was on aricip and how I can remember to say don't ask me, it must be the divine Holy Spirit.
I: Who do you think should tell you that you have dementia? Do you think it should be your GP?
R: Ah in hospital, when your, sure your getting looked after for like, your getting all the....
I: Do you think a family member should be present with you or a friend present with you?
R: No, I could be going to hospital for so long as well, sure you could be four or five hours up in that hospital, and there's nobody can, can stay away from their, you know.
I: I just have a few more questions for you?
R: I'm after been thinking you'll have to write down and tell me what you're trying to get PhD, is it?
I: It's a doctoral in social studies, to become a doctor. Not a medical doctor.
R: Not medical?
I: Not medical.
R: What kind of...(pause)

I: You study for three years and you do a big project and you specialise in a particular area. So I'm looking at, I'm in social studies; I'm looking at social policy. So I hope to become a specialist in social policy for people who have dementia and Alzheimer's.
R: Oh very good. Do you want another cup of something?
I: No thank you, I'll be up and down to the loo.
R: I'm going to rely on you. It would be great wouldn't it, the cancer now, when we go to the celebrations of life.
I: What's that?
R: It's giving thanks like, it's on twice a year and current professors, right that are working and professors that have retired they speak and some patients and only for the research that they tell you how many, many, many more would have died without, without the research. And I host, they only have allowed it the daffodil sale day, they only have allowed it at J------ hospital in the last four years, J------ and last year with myself and five others doing two hours on and so on, we raised, what was it, we raised five thousand and less than a hundred euro like you know.
I: Very good. Do you feel you need advice and support, would it have been useful to you?
R: Ah yes.
I: What kind?
R: Like if it was, like a little meeting that you could go to, people have that have this struggle. To have a chat like you know....
I: To say I have memory calendar what do you have...
R: Exactly that's it exactly now Emer. Or if there was any dances at all.
I: Social outings?
R: Yes, yes. That's right.
I: Did you ever contact the Alzheimer's society yourself?
R: No but the last day I was at that hospital, up in ------. The lady doctor I never saw her before, and she was very nice, and they really are all very nice, and ehh, she said that she was going to contact whatever or whoever and I didn't hear anything.
I: Ask them again now tomorrow.
R: I will ask. I didn't hear nothing.
I: You know you can ring up the Alzheimer's society hotline, they have like a ...
R: Ah a few times I was looking at the add with the man sitting on the chair on the sofa. And it says and eh, I was, I got to write it down.
I: What did you think of the add?
R: I got to write it down I don't know after how many times and emm, but then I said well the hospital said but I didn't hear anything.
I: Do you think the add with the man sitting on the sofa is good or bad?
R: I think he's nice, I think it's happy. But I'll tell you what was very sad that poor woman over Christmas in Bray that went into the lake, I don't know where she went.
I: That's right, that's right. She drowned out of the nursing home wasn't it?
R: What happened to her, she was never found anyway at all.
I: That's right, it's very sad. You do have a good memory you remember lots of different things.
R: That poor woman imagine. Oh my god, help her.

I: I'm just going to ask you four quick questions about preference. Do you like to watch television?
R: Only nature.
I: So that wouldn't be very often?
R: No.
I: And do you prefer winter or summer?
R: Summer.
I: Summer and which of these colours do you like the best, yellow, green or red?
R: Oh, red... can you say two?
I: Yellow, green or red, no you can't say two, oh you can of course. You can have two.
R: Can I?
I: Yeah, yeah.
R: Yellow and red.
I: Which of these ways do you like to have your eggs cooked, scrambled boiled or fried or you don't like eggs?
R: Boiled.
I: Boiled OK. Emm are you managing OK with your memory problem at the moment, with the dementia?
R: Yeah, yeah. I'd be just say, this priest I knew had Alzheimer's and he couldn't never say mass for two years, up at -----'s parish, and then, I have a photograph, where, anyway he died after, he did get back to mass, to say mass and his name (pause) I don't, I'd, but he used to be confused, somewhat not remarkable, now not desperate. When eh got back to saying mass, and I do just wish, will I tell you what I do just wish?
I: Go on.
R: I just wish that I wouldn't like to have to go into a place where you would have to be minded. I only wish that I could be like even this way all the time. And that I want to be able to help the girls and help everyone and be able to do the guiding. That is what I would like. What I wouldn't like and I wouldn't like in the sense not to be here where I live. You know what I mean Emer.
I: I do, I do.
R: That's really all. But Father ------ I do say to him about that, I do say if you can do anything that and just be no worse. *(Mrs Beattie places teabag on the outside window ledge and says* 'I do collect them teabags for the flowers, did you ever hear of that? I: No. R: Good for them, it's them my cousin told me and I thought he was joking and I didn't want to kill the flowers, but it's like ehhh.... I: Fertiliser. R: Yeah).
I: How's your confidence and your self-esteem?
R: Oh yes, I do notice Emer I'd rather be very much prefer to be on my own. And yes, that is the truth now.
I: Why's that?
R: I'm not, I prefer, I don't like making decisions as well because if I do and then I don't feel, if I feel all over the place and I don't want to go, you know. I don't, I don't want to be there that I couldn't cope. That's, yeah... (pause)
I: So you don't place yourself in those situations. You're not as quick to place yourself in those situations?
R: No...(pause)

(The telephone rings, it's Mrs Beattie's GP. He's ringing about her earlier query around her anti-biotic. There is a scramble to find the medication information sheet. Mrs. Beattie has a brief conversation with him).

R: He's a family doctor and he has three boys. And his wife helps down there sometimes, his sister is for if you're expecting a baby, she works down in the same A---- is her name. And his wife is lovely. Three boys.
I: You are well involved in the community I think, you know people in the area and you're active in the area?
R: Ah yes and the poor blind people. But where you are doing that, they, and there is a lovely couple I'd love you to meet them. I'd give anything. P-----and H----, P----- was born blind and came to where you get help when she was only four and her husband H----- wasn't born blind or anything and never had any defects until ages 35 then eh lost the sight. And he had to go where P----- had been and he was still, and is still and they got married.
I: That's lovely. You mentioned earlier that your confidence wouldn't have been as high as it was before?
R: Ah yeah.
I: Would you have had high confidence before?
R: Ah no, I'll tell you now Emer this, I, I never would be a leader but where's though I like to help and I worked in the parish for very many years, the caring and sharing association. But then I stopped when ---- was very sick. But I like to be able to help people.
I: Do you have a good social life now?
R: I might be going to Medagoria if I'm able. But now really this, say the week gone and say today, I'd say no I wouldn't be able. I couldn't.
I: Why's that?
R: Because I wouldn't you know. What do you call that word? If I don't know what you call it, if physically, is that it, bodiness rather than the head is so evident maybe this part. Oh but I would be terrified as well but I wouldn't go away anywhere where I wouldn't be able to see who I would be with you know.
I: Do you go out with friends?
R: No, no.
I: Used you before?
R: Yeah, I'd be the ringleader.
I: What happened?
R: Ah no, I, I, I'd be too tired but I think it's all them tablets maybe. And sure what I was going asleep and the doctor in ----- told me that.
I: Do many friends call up to the house?
R: No. The doctor in ----- told me that if I feel, I have to sit down and if I go asleep all the better. Sure I love, I tell you what I love, the afternoon show.
I: The two ladies.
R: The two girls. And I was back in time from the doctors and that I never saw it, I can't even remember what I saw but it was over and everything when I woke up, it was six o'clock when I woke up.
I: Do you do all the house work yourself?
R: Yeah. Only sometimes.
I: What do you do the rest of the time?

R: Sometimes it would be like oh my God, and I say it doesn't matter, I can't make no shape or make on anything. And eh, and I say ah I'll do it tomorrow, do it later or yeah but.
I: Do you look after your daughters children?
R: I'm not able now. No only that this is only I have to be *(she has to be out at her daughters at 2.30 to help with the children)*, G---- her neighbour opposite is taking, E----- is only barely gone back to school she was in hospital for eight days, her little girl and the little boy has dyspraxia and dyslexic. But I'll show you his photograph. The little fella, he's gorgeous, a little dote
(Mrs. Beattie shows me family photographs and tells me stories about her family).
I: Are these the only two grandchildren you have or does ----- have any?
R: No Liz has ----- she's eleven, she has three inhalers with the asthma *(this explains her grandchild's cause for going into hospital)*. They still don't know in ----hospital what was wrong with her.
I: You're going out then just to help out?
R: I'm only going over to be, I could wait in Gi----- ... (pause)
I: You're getting collected are you?
R: No I'll drive, I do know the days that I can't.
I: You are very aware?
R: Oh yeah. Oh I certainly do. I know but ---- has to take ----- back for more blood tests, fastings and they would ring if there was anything of importance and if not go back in two weeks. No ----- has ovarian cancer, only one year married and so then none of the chemo, 29 sessions worked. And then she only had an option to 50/50 either way that she would live or she would die, have everything removed from her body, the reproductive organs and she got that done, she went for it. She said to me Mam, and then under micro-scopic they diagnosed two cases in her liver and she wore three life lines, you know the hickman, have you heard of hickman because the chemo broke down the veins but it was then, it was the last lap after having all the 14 hour thingy operation for it, everything going well and then when they took her in 14 weeks after the big surgery to do the liver, two massive chemos they were going to give her and it was then that they thought definitely that she wouldn't live. And ehh, even before she went in and they thought she wouldn't live --- used to be crying and I used to be crying, and she said I'll get a liver transplant if it doesn't work. But she lived and then Professor, he was doctor when ---- went in and he's Professor ----- ------ ------, in J----- hospital and he studied the priesthood for four years in Maynooth. But god wanted him to be, he's a medical oncologist. He said, whether or not what you might think, 'cause never ever did we expect you to live, it's the higher power he used to say to her. But ------ it is the higher power like that. He would say to ------- if you live, and live in remission, adopt a little child, a Chinese baby girl.....
(Mrs. Beattie went on to explain her daughter has since fostered three children. She showed great insight and compassion. She took out more photographs for me to look at).

I: Would you take a drink?
R: I don't drink but the doctor the last day said I have to stop smoking.

I: How does that make you feel?
R: Oh, I, I haven't done it rightly yet. She said, the lady doctor that the smoking was going to help ya. She said... (pause)
I: Do you have a good quality of life now? Or is it bad or someplace in the middle?
R: In the middle.

(Mrs Beattie shows me more photographs)

I: You're family seems very important to you in your life, are there other things that are important?
R: Ah no.
I: The family.
R: Yeah and my brothers. I'll show you them.

(She shows me photograph of her husband).

R: You'll have to call around to see me again, will you?
I: I might call again next week, if that's ok?
R: That's ------ there my husband and he died of lymphoma at 48 years, nineteen years tomorrow I think, no oh no, not tomorrow he died in October.
I: Did you have a good marriage with him?
R: Yeah, he was a bit like, you'd be afraid, like he was very highly strung, highly strung. Couldn't help it but ------ is the very same. And ---- is like me salty, come they go they.

(Mrs Beattie shows me photograph of her brothers. One of her brothers has throat cancer at the moment but "is doing well". She had a sister that she was never told about who "died aged two and a half, she would have been my aunt told me, if she had of lived she would have been a little small person and if I see one of them I can't stop crying, ------ was her name")

I: You are the youngest then in the family?
R: Yeah. And I'm thinking what am I going to do everyone will be dead before me because I am the youngest. And I used to be really terrified. That's the truth.
I: Would you have many friends? Close friends?
R: Emer that is the truth.

(She puts pictures back)

I: Are you able to do all the tasks around the house yourself. All the cooking and cleaning and financial matters,?
R: Well I do it I tell ya. I'm on my best behaviour now because I knew you were coming. I'm telling you the truth now Emer.
I: You're on your best behaviour now?
R: That's what I mean.
I: Are ya, why's that?
R: About the house. Ah no, I'm, ah no, ah no.
I: Does the Public Health Nurse ever pop into see you?
R: No, she came once, after I was not going to Occupational therapy. Right she came once from the clinic up there and she was

very nice, she, she ehh, she wrote down millions of things and then I don't know. And then I don't know why I was wanting to get in touch with ------ hospital and I went up there to that clinic and I explained and the girl said oh go on in there, and the nurse had me down she said she had no recollection or no, she couldn't remember. And I said you were in the house, I said for a long-time and had tea and a few scones, and then when she heard the scones, she had me down under a wrong name. completely, but no.

I: You don't go to any other day centre now at all?

R: No.

I: Would you like to go to one?

R: With Alzheimer's yeah?

I: Or a regular retired, for people who are just at home.

R: Where would they be though?

I: There's a few around here. There's a few day centres. They come and collect you, there's one down in ---- road, down in ----.

R: Yeah.

I: That wouldn't be too far away.

R: I think that's where, I have this friend, would you like another cup of coffee?

I: No I'm grand thanks?

R: I have this friend and her husband had Alzheimer's and I think that's the name of the place she said he goes.

I: Would you like to do something like that?

R: What would you be doing, talking and chatting and?

I: Yeah and they do bingo and different things and...

R: Yeah.

I: Just to kind of get you out of the house and to.

R: Have a bit of commitment. Yeah would you write that down for me, what I have to say. 'Cause when your gone here I'll be, now what did Emer say. I'd love to know and I can't remember anything without writing it down.

(Mrs Beattie goes to get a piece of paper)

I: You want to ask about the aricept as well don't you?

R: Yeah.

I: What do you want to know about the aricept, it's difference to exelon or...

R: That if, would it be better for me with, if I could take it with something that wouldn't make me get sick or am, do they think maybe it's better to leave things well enough alone. I don't know. I never finished telling you about that friend when the phone rang, about couldn't find the piece of paper and in Britain there was this man had written that he was on aricip and it was his sister who lived in a different part and emm, I think B------ was saying that it was because they were much more expensive the aricip that they didn't deal with them for the sister but that the brother was much better, was getting on much better. Then again that would depend on your head, mightn't it.

I: You involved in any other clubs or groups? You said you do the things for the blind people?

R: Ah yeah.

I: You enjoy that?

R: Ah yeah, you'd be crying, walking along you have to tell them if it's the time when you see swans and don't you know and your really

sad, your really sad for them. But they're really happy people. And H---- that went blind at age thirty-five do you know what he is? A computer analyst.
I: You still drive the car as well?
R: Yes, I do, up to the church, up to the local shops to, to J------ hospital to that brother?
I: You showed me the picture of?
R: Did I not show you two?
I: You did yeah, you took them back again, I think you put them inside.

(Mrs. Beattie explained why her other brother is in hospital. He has advanced Parkinson and was burgled and thrown to the ground resulting in a dislocated shoulder and broken bone, as a result he has been in hospital for six months. For the last three months he "is all confused and wants you to bring him home". His wife also has some mobility difficulties).

I: Is there anything you'd like to do that you're not able to do?
R: I wouldn't mind, I would like, if it wasn't far from here, kind of wouldn't mind to go see some-one that can't go out, do you know.
I: To keep somebody company?
R: Yeah. Something like that. Then the only problem about that Emer is you see, as well. Is if I felt terrible like sometimes I feel afraid, I feel afraid and I wouldn't have, you know, and then if I couldn't go, I wouldn't be, well a challenge is good I know that but if I didn't then I would be all upset you know that way. But for the person, do you know.
I: Is there any major thing you face regularly or any little thing everyday that is kind of frustrating or..?
R: Trying to remember, oh yeah.
I: Do you have any future fears?
R: Fear that I wouldn't be able to cope on my own.
I: Are you receiving any help from anybody at the moment?
R: Like?
I: Like Public Health Nurse, home help, meals on wheels?
R: No.
I: All you're doing is attending ----- and your GP?
R: Yeah but you can only go to ------ when you have an appointment?
I: Of course.
R: Oh yeah. Like I couldn't go up. I was going to even make, when I'm up on Wednesday I'll tell, you see some of the doctors are different than others, then say about this thing, I'm glad I went to the doctor my own doctor because I wouldn't even be able to go to the hospital tomorrow if my head had of been the same, so it's helping. So long as I don't blow-up. Well I'm after, you're a witness.
I: He said it was OK?
R: He said it was OK.
I: Would you like somebody calling into see you more regularly or anything like that?
R: I, like come in for a little chat?
I: Yeah, or somebody else coming in to make sure your all right health wise.

R: Would they tell you when they're coming?
I: Yeah of course they would.
R: Yeah I don't mind.
I: No this is up to you.
R: Oh yeah.
I: I can't provide that for you.
R: Oh I would or I'd like to go to the place I said, where the people would be like yourself.
I: The support kind of group.
R: Yes, yes. That I would do. So long as you were brought there and brought back.
I: You'd need to talk to the Alzheimer's society.
R: Yeah I'd say so, so I'll get that number of the telly with that man.
I: And ring them up and explain your situation and just see.
R: Yeah, yeah.
I: That's' a good idea. And has your attitude towards memory problems and Alzheimer's disease changed at all?
R: I wish I hadn't got it, that's what I wish.
I: Do you think there's a stigma around it?
R: I really wish, you know that's what I wish because I think I can cope with anything in this whole world better in a sense than this, because you're totally lost sure. You're lost, you're like a child. I feel sometimes like i'd like to be when I was able to do the work at the driving school and even in the shop, but now I wouldn't be able.
I: Did you find me coming out chatting to you all right?
R: I'd like you to be staying all the time. I would.
I: Is there anything else you would like to add before we finish.
R: But I would.
I: Why's that, are you lonely?
R: Well I like, like you, I do. I like everybody really, ah do, I do really. And I wasn't a bit afraid, I didn't feel once afraid, didn't.
I: When?
R: Now today.
I: Oh very good.
R: Not once, and I feel as well that if it was to help you.
I: And it was, it was very helpful.
R: If that it could help you.
I: Well it did, you said some very interesting and important things.
R: Did I?
I: You did, yes. And it was from horse's mouth, some-one who was experiencing it themselves which is mostly important.
R: Now well, I do now say if I can't know where something is or if I don't know where something is, or if I don't lock the car or forget like, and all and everything and go to other people's cars, I do say ah well, well it could be worst so it could, that's about it.
I: Well thank you very much for having me. And what...
R: When will you come again? Won't you ring me?
I: Yes of course, I might come back again.
R: Yeah.
I: It will probably be Monday or that I'll ring you just to see about coming back out. I'll ring you.
R: Won't you because I wouldn't like you coming when I'm not here.

Transcript: T0 030, Mr. Murphy, Respondent with Dementia

Conducted on: the 13th of June 2006
Conducted in: the respondent's home
Interview length: approximately 52 minutes

R: It's grand I would go out at 8 o'clock and have a cup of tea about this time you know and then go out again *(Mr Murphy his speaking here about doing his garden)*. Then Margaret would be coming in about, she would be late now in the evenings these days when she's on her own. Get her dinner and that's it.
I: Can you tell me a bit about yourself? Are you retired long?
R: Great time. Emm, ninety, I think it was '91 or '92.
I: You're not originally from N--- though are you?
R: No I'm from Dublin.
I: So when did you move down to this house, many years ago?
R: Oh that was when I retired, when I came into this house but I was eh, emm, renting houses around here you know. then when I got the ... when I got the thing from the government or the, the pension and the lump sum you know which at the time was 90,000 you know. And I get a pension that is indexed you know every year. So it's all right.
I: What did you work at?
R: Oh I worked in Aer Lingus and I was a chef for 13 years and then I got into management you know but that's no big deal or anything like that but... (pause)
I: Did you enjoy it?
R: Ah Butlins (laughs).
I: In Aer Lingus was it?
R: Yeah at that time, at that time. It was a grand place.
I: Are you married to Margaret for long?
R: No only last year. Only last year. We were living together for a long time, my wife died. I got separated from *(coughs)* my wife and then she died so. And we got married and ... (pause)
I: Would you say you are happily married?
R: Now?
I: Yeah.
R: Jes yeah (laughs), yeah, oh you'll, we'll have an odd row every now and again, nothing to it.
I: You mentioned you are 70 so you were born in...
R: I'll be 70 this year, '36.
I: I could have done the maths but *(laughs)* and you were born in Dublin.
R: Yeah.
I: Are you just on a State pension or are you on a pension from your old job?
R: Eh the pension, from the government and from the ... (pause)
I: Job, yeah.
R: Emmmm.
I: What about children, do you have any?
R: Yeah two.
I: Do you see them often?
R: No. No there's a ... (pause) A fallin' out sort of thing over, I'm, my first wife died you know, there's a row over what way the house goes you know. So I'll tell you what happened emm, they wanted to give

me something, they told me the house was worth 400,000 to 450,000 and they were going to give me 40. So I took it over and I'm after selling it from 625,000. So it's all going through a solicitor and they're getting to much fuckin' money anyhow (laughs).
I: Do you find it, I'm sure it's very upsetting?
R: It is because I don't get to see the kids and that you know. Maybe they're, they're annoyed because I left Kay or something like that you know which they would be entitled to. But apart from that everything is all right.
I: Does Margaret have any children?
R: No, no, no.
I: Emm so it's just the two of you in the house?
R: Yes.
I: Can you tell me a little bit about your memory? How it is?
R: Emm, I can, I can go back to footballers, club footballers that sort of thing you know, I can remember the wars and all that sort of thing. But it's not to, the doctor said it's the beginning of it you know but I think it's a bit more than that you know. I'm getting by anyhow.
I: Why do you think it's a bit more than that?
R: Ehh, I can get, I don't get annoyed, I do have to turn to Margaret, if we're in the pub, I go to the pub twice a week you know, Friday and Sunday you know and they were talking and I wanted to say something and if it doesn't come I have to say Margaret what am I trying to say, but she can't, she can't get into my head you know.
I: So is it like you can't find the words or you're in the middle of the sentence and you ...
R: Both, yeah.
I: Don't know where you're going with it?
R: Both you might say oh this happened and thing, what was it that happened you know. but I don't worry about it, you know I'm not, at the moment anyhow I'm not and I suppose if it gets too much I won't fuckin' know anything about it, sorry for cursing. It's a I won't know anything about it.
I: You won't be aware of it?
R: No.
I: How are you with you're friends?
R: Ah no, ah no, emm, I have good friends, one across there and one up the town and some down in Kerry. You know.
I: That's good, and what kind of things do you forget?
R: Em
R: Would you ever put something down and forget where you put it or ...
R: Oh all the time, all the time, I would be going into the bathroom for a shower or something like that and where is my bloody glasses, where's my bloody this thing you wouldn't know.
I: Do you ever walk into a room and kind of go what was I coming in here for?
R: Yep.
I: Do you ever forget people's names or faces or anything like that?
R: I'd have to say yeah, you know when I was down at that ... (pause) the grave yard there *(he had been at a funeral that morning)* I said what's his name and they were great friends.
I: Is it having any kind of effect on your relationship with Margaret?

R: She would say what are you trying to say, you know, I'd say I don't know what I'm trying to say you know. We'd be talking about something and it would dry up you know.
I: But you get on well other wise?
R: Oh we get on well yeah, yeah.
I: Does your memory ever affect your mood?
R: No. No it doesn't I'm trying to figure it ... (pause) I might get, I might get eh... (pause)Give out to Margaret as if look I can't remember the fuckin' thing you know, if she said, sometimes she asked me to do something you know and when she comes in oh you didn't do that ah sure I forgot, ah sure that was an easy thing. I'm great in the house you know, I don't do much cleaning up in the house now that's being honest with you but you know if, if there's friends, we bring friends down now and again for dinner you know, there would be 8 of them and that I would be all right then, like I can breeze through that, and that sort of thing. So that, that's with my friends it's grand you know we sit down there and we drink too much (laughs).
I: When did you first notice it?
R: Now that would be a no brainer because I can't remember (laughs).
I: (Laughs) I thought I'd ask anyway you never know.
R: I would think about two years. Two years.
I: Were you the first person to notice it?
R: I don't think anybody said anything about it. Yeah and I suppose maybe I was the first one. You know it's like what you were saying if I was going in there for a pen or tablets, where did I leave them last night and all that sort of thing. Normally I'd put them in here and then sometimes I'd bring them in the thing and then where did I leave them.
I: Who was the first kind of you know professional person you spoke to? Would it have been your GP or?
R: About my head?
I: Yeah.
R: That was in P-------, that was in P------- I was in P-------- for ... (pause) for two weeks, it was to be doing gym stuff you know but not like the professional fella's, it was a grand thing and we had, I loved it there because not only were you getting looked after, but the craic was great with the nurses and the physio, or the women that look after you do this, do that and that sort of thing. It was really good. And it was in October and you could walk around huge big, I don't know whether you know it or not, but there's huge big fields in it and all and it was great, you could walk around there and I love walking around. But with hills now I, they're a no, no.
I: Why were you in there for the physio? Did you...
R: The lungs. Yeah. So I keep on laughing to myself about it you know, there's three things wrong with me, my heart, my lungs and my head. It's all you can do it laugh.
I: You have to keep your sense of humour don't you?
R: I sort of think so yeah. Doctors were coming in and I just said to him look there's something wrong with my head, like there's things I can't remember and all this sort of thing, and he said OK I'll get another doctor. And that's the start of it, I got, I got scanned and all that sort of thing and they said it was the onset of it. You know. I've often, well I didn't often read but they were talking about it or it was in the

paper where you get tablets for it you know, but it's only good for a year. Did you ever hear of that?
I: Yeah.
R: Well I said what's going to ever happen after that year.
I: So are you on those tablets now?
R: Yeah.
I: How are you finding them?
R: Well... (pause)
I: Have they helped at all?
R: I don't know, I really don't know. I really don't know. I tried my best to do the, the cross words and all that sort of thing and what would happen now I'd be looking at it and that's across and that's that thing and then I'd say what goes there *(illustrates the work following on from the clue he completed)* and then when I'm looking at that, you see I don't put it in, see just make sure that it comes this way you know and then I go back and I'm after forgetting, that's the one thing that I notice.
I: That's frustrating?
R: Well yeah, so now when I see it going across and see that now I write that on the side of it first and then ... (pause) I'm not great at it.
I: You have a technique for doing it?
R: Yeah.
I: Do other people around you treat you differently now?
R: No. I don't think no, I don't think so.
I: OK, emm, and do you find the memory problem frustrating?
R: I don't think so. At the moment anyhow. At the moment. I do always say to Margaret ah shit Margaret I can't remember what I was going to say to you. I might be sitting here and there would be something on the telly or something on the radio and I go in and then I forget it.
I: Would you say you have always been good at coping with things throughout your life?
R: Whatever that means.
I: Well if anything major happened in your life that you were able deal with it. That it didn't overwhelm you.
R: I don't think anything ... (pause) Eh... (pause) would maybe I was just lazy that it didn't come in you know (laughs). Well let me put it this way the only way I can think of it you know, brothers and sisters that died you know there was nine of us. And emm, I don't know if you know, my mother lived on she was 101 when she died. My father died when he was about 75. Now he had the same as me, you know the smoking. And my sister was the same, she was smoking, she died a bad one but I don't think so, I don't think so.
I: Are you still smoking now?
R: No, no, I used to laugh at myself you know when, I think it's nearly a year and a half I don't know, but emm Margaret still smokes and I say look I'm not telling you to stop you know but just look what's after happening to me. I think you can only, only you can get off cigarettes nobody else can help you. They'll, if they want to, you'll help them, you know but until they want to, you can't do anything about it. But if she, she smokes anything she might have two, one in her bag and one would be here in the evenings *(points to coffee table)* and she'd go out, this was when I was only starting you know to get off them and that would be there and I'd take one out and I'd

put it in my mouth and it was in the winter and I'd put it in my mouth I wouldn't light it and then I'd throw it in the fire. And that did me for three or four, four hours you know, you'd be gone, you didn't want it.
I: It fulfilled the need for that length of time.
R: Yeah.
I: How would you rate your memory problem, would you say it's very good, good, bad, quite bad, or very bad?
R: Say that again.
I: How would you rate your memory problem would you say that it's not very good, good, very good bad, or very bad?
R: I think it's the one in the middle.
I: OK and do you think your memory problem will in time return to normal?
R: No.
I: I met you when you were up in -------- hospital...
R: That's right yeah.
I: I think that was the day that you were given your diagnosis, that's when the doctor told you what was wrong I think.
R: Yeah that was, that was a bit scary, you know. Were you sitting there when he was talking to me?
I: Yeah, yeah I was. How did you find it?
R: Well I think he talked more about driving and fuckin' everything, sorry, driving you know, get onto your thing and get, got to a solicitor and whatever that thing ... (pause) see I can't remember.
I: Enduring power of attorney.
R: Yeah, he was telling me all these things, he wasn't telling me anything about my head.
I: Did he explain to you at all about what was going to happen in the future?
R: Not that I can remember. I had to say to him, I had to say I think I said to him, hold-up you're talking about driving, and that.
I: Enduring power of attorney.
R: Yeah but what about my head. And, and I, and I don't know whether he said it but somebody said it's all right for a year and after that you don't know what's going to happen.
I: I think everyone experiences it differently and it's very individual and some people can have the illness for a long, long time and for it not to progress very much so hopefully in your case that's what will happen, hopefully.
R: Ah grand, grand I'll be looking forward to that.
I: Ah but you know what I mean.
R: Yeah hang on to something.
I: You have to have some level of hope as well don't you?
R: Yeah, well I have good friends and all that sort of thing and ... (pause) they don't say, they don't say anything about you know, god don't mind him he doesn't know what he's saying or anything like that they're not like that, you know. They don't, what's that word, ostracise ya you know, if you're in a crowd you're not stuck with him, they're not like that.
I: And would you have liked more time with the doctor when you were in --------?
R: I don't think, well, I don't think, well what I said to you first was you know, you know get the power of whatever and get onto the driver, them things and all, he was on about them things and then other

things and all sorts of things and then when I asked him, well right what's it going to be for me? And I actually said to Margaret you know he sounds like a fella whose touting for you know the, ah feck... (pause) the insurance and all that sort of thing, or the insurance people are telling him anybody comes in with that tell them to ... (pause) you know. But that's all over now I'm getting on all right at least I think I am.
I: I think you are as well. OK...
R: Would you like a cup of tea or anything like that?
I: No I'm grand, you get one yourself there if you want.
R: No I'm ok.
I: What did you do afterwards did yourself and Margaret talk about it.
R: No not really, no.
I: Have you talked to your own GP about it?
R: Ah yeah, yeah, I do laugh at it. You see you know, the lads are how are you doing and all that sort of thing and it's not being the poor boy you know, sure my heart was done years ago and now my lungs are done and now this here that's not right *(points to head)* so it's the three, three. I just make light of it if I can you know.
I: I think that's a very good way of approaching it.
R: I don't why, you know. I don't why, whether I should be moaning about it, what's going to happen to me.
I: Would that make you happy if you moaned about it?
R: Not at all, no, no.
I: I think that's the most important thing, yeah, yeah. And would you like to talk to somebody about it more?
R: Emm... (pause) What good would it do? I don't think it would do any good, unless somebody comes up with a big pill and says put that in your head and everything's all right, and that's not going to happen.
I: What about going to a group with other people that are experiencing the same things as you? Would you do that?
R: Well why, you know if I went to a ... (pause) this might be, looking after yourself what I'm going to say you know if I was in a crowd, not a crowd four or five, or six or seven you know, and you hear them moaning and all this sort of thing I couldn't stand that. And that would annoy me. I'm, I don't know whether I'm in, I'm alone in anything but I, I don't like, maybe I'm talking to much... (pause)
I: No you're not.
R: I don't like being in a place where people are moaning all the time.
I: I think these types of things suit some people and they don't suit others so its, some people love that and others...
R: Yeah because they want, they want them to, they want other people to say ah look but then not everybody is the same. And I tell you I'm talking an awful lot, more than I ever have (laughs), they're things coming into my head that I wouldn't even think about, you know.
I: Is that OK for you?
R: Oh yes, oh yeah.
I: And did you tell your friends and that when you got the diagnosis?
R: Ah yeah.
I: Did you let them know?

R: Yeah, they'd say oh it's your round now for the drinks, ah Jesus no I think I did the first *one* (laughs).
I: You need to keep a notebook with the time and the amount you bought (laughs). Do you feel you have enough information about what is happening?
R: No, because I think there is not too much, not too much you know you ... (pause) I don't think they told me anything when I got the scan, I don't, I can't remember them doing anything like that say ... (pause) The girl where I got it done she was showing me slice, a slice, a slice you know, well you know, well she says that slice isn't too good, that one is great and all that, that's what I got, no I don't think they told me. They said the tablet that they gave me they said it would do for a year. And I can't remember when I got it.
I: It's not too long ago because I saw you within the last couple of months. Were you glad that Margaret was with you during these appointments or would you preferred to have been by yourself?
R: Oh I would, I would, I would like her there yeah. Yeah... (pause) Margaret would have to know, you know and if I go in on my own and I come out and I can't remember what to tell her you know, what's fuckin' wrong with you, you know. Are you codding me (laughs).
I: Do you think you would have benefited from discussions with a social worker or somebody like that?
R: Probably yeah. I think you should, I think you should get somebody to say look this is what it is, you know, it mightn't be, it may be, and it certainly will be you know. Tell me which it is. But maybe, I don't think they know themselves.
I: I think it's like what I said to you before, because everybody is different you can't make generalisations about it. OK I'm going to ask you four quick questions they might sound a bit silly.
R: Go ahead.
I: It's part of a scale. Do you like to watch television?
R: Yep.
I: Do you prefer winter or summer?
R: Oh summer.
I: And which of these colours do you like the best, yellow, green or red?
R: It doesn't make a difference.
I: And which way do you prefer your eggs to be cooked, scrambled, boiled or fried?
R: Fried.
I: It's a silly scale.
R: No, go ahead.
I: OK so what's life like managing with a memory problem at the moment?
R: What's what?
I: What's life like for you?
R: It's ... (pause) See I can't say the word, it's terribly when you can't get the word out like right now... (pause) That's the hard part, that's the hard part.
I: Frustrating part I would say?
R: Yeah it is.
I: Does it effect how you view yourself?
R: No.

I: Would you say you are a confident person?
R: Yeah.
I: And has that changed at all since before you got the memory problem?
R: No, no, it's just this thing you can't say what you want to say it won't come out.
I: OK emm, and how would you rate your social life at the moment? Would you say it's good or bad, or in the middle?
R: Ah it is, it is good.
I: Has that changed at all in the last couple of years?
R: No. not with the friends I have anyhow you know.
I: You have a good social network?
R: Ah yeah.
I: How would you rate your quality of life at the moment?
R: Good.
I: Has that changed at all in the last few years, got better or worse?
R: No.
I: OK and what factors are most important to your quality of life?
R: Being alive (laughs).
I: That would be the main one wouldn't it?
R: Yeah, emm I tell you what the draw backs are, I think I said that, if I'm going on holidays it has to be on a flat place you know. Hills are out, hills are out.
I: Is that because of your lungs or your heart?
R: The lungs I don't know ... (pause) mostly the lungs I think.
I: Would you get away on holiday much?
R: Ah genie yeah.
I: Would you go like abroad?
R: Ah yeah, I was down in Limerick, I have family from Canada and that's about a month ago and that's nearly 25 years before I went on holiday in Ireland.
I: Really, and where would you normally go to?
R: Ah the Canaries, Canada, and I went to South Africa once. I wanted to go when I was younger but if you went to South Africa your pass port it would be stamped and you wouldn't get into other countries so Margaret wanted to go to Miami and I've been in Miami long ago so I said no I want to, I've always wanted to go to South Africa so we went.
I: I'd say that was a trip of a life time was it?
R: It was a long old hike, oh yeah I can't remember how many hours it was.
I: Do you have a daily routine at the moment? You mentioned when the weathers fine you spend most of your day in the garden?
R: Oh yeah up and out, up and out and I'm going to be straight with you in the winter all you can do is look at the television. And do whatever.
I: Do you read the paper?
R: Oh genie yeah get the paper and do the crossword, try and do the crossword and... (pause)
I: And would you be a big reader anyway? Like books or ... (pause)
R: Well when I got the bypass I, I, when I got the bite-pass oh God the bypass eh, I sort of couldn't sort of concentrate on, on eh reading. Now I don't, now here I have some books that I bought when I'm going on holidays, I bought two books the last time. One of them is

one thousand two hundred and things in it (laughs), you know, I just bought them I didn't look at the thing. And the other was nine hundred and something, and I just didn't get through the first one.
I: Would you be interested in getting these you know, emm, like books on tape? That ...
R: Haven't a clue about it.
I: You'd buy a CD and it's got a book, somebody reading out the book on the CD.
R: Ah that would bore me, somebody else doing it yeah.
I: That's fair enough. And you mentioned that you have a couple of little techniques to support your memory, like with the cross words you write it at the side, is there anything else you do? Would you have a calendar where you'd write down your appointments or a dairy or anything like that?
R: No. Well, well tell me what maybe you don't know you're just asking me stuff along those lines I don't mind that but I, I hospitals and all that sort of things you know, Margaret has all that you know, I would never know, I think I have to go next week.
I: You would never have known?
R: I might if I was on my own I'd miss it. Maybe that's, Margaret is a strong girl you know, she's very strong. Eh sometimes she's too strong when she's ... (pause) I have a thing now with the solicitors there you know. You would want to hear her, the amount of money they want to do... (pause)I'm going to tell you. Eh I sold the house for, well I didn't sell it, the, the, you see the kids they said it was, I was leaving it to them and they said it was between 400 and 400,000 and 50, no 400 or 450 you know. I took it over and its six-two-five that's nearly 200 more so I don't know whether they were screwing me or something like that you know but that's all coming up now and it's a lot of money going into that.
I: It's upsetting as well.
R: That's what, that's what, you see Margaret would get on to them, I'd be telling you she'd be fuck you, you're not getting that money and all that sort of thing. And I hate to hear that. She's feisty like that, yeah. But apart from that.
I: Like the funeral this morning that you went to, would you have remembered to go to that or would Margaret have reminded you, or somebody else reminded you?
R: If I... (pause)
I: You know the funeral you were at this morning?
R: I knew that because Margaret went out and she's working and she was on, she was in the office on her own because somebody left and emm on Saturday I had to ring her and say come on, come on, come on, get out.
I: So do you do your own cooking?
R: Absolutely great.
I: Good and you mentioned that you're not great with the cleaning, around the house?
R: With the cleaning? Not too much around the house, but it eh, eh, eh but we have maybe six of four maybe clean up that, maybe some of them would get up and maybe they'd do it you know, they're like that.
I: What about the shopping, would Margaret do t he shopping or would you do the shopping or both of you?

R: I used to go with her you know and now she goes on her own and I do get annoyed then when she, you see I was a chef as well and you know she'd come back with a piece of meat and sure I say that's shit you know (laughs), as hard as anything you know. And I hate stuff that comes in plastic. Anything that's in it, I hate it. I hate it.
I: Who looks after the financial matters in the house?
R: Margaret.
I: Has she always done that? Or would you have both done it?
R: Ehhh, ... (pause) I used to do it. Because she wasn't working at the time. And then she got a job and you know, she said I'll do this, I'll do that and I said you do, I'm a saver she's a spender.
I: Has the Public Health Nurse ever called into you?
R: The what?
I: The Public Health Nurse?
R: No.
I: What about the emm, meals on wheels?
R: No. I could sell them.
I: You could do that. A home help?
R: No.
I: Would you see your GP regularly?
R: Yep. In the pub. He goes to the same pub as me. But I only go on Friday and Sunday you know.
I: And would you have a good relationship with your GP?
R: Great.
I: And is that important?
R: Yeah because I can ring him, I ring him and I always say to my friends in .... '84 when I got the belt he got me into N-----. And when I come out of N----- I didn't know what was happening so I went down to him you know, and said so what's going to happen now. Ah says he lets see. I was in... (pause) I was done in the Mater, there was another hospital in Dublin, can't remember, dirty old place though.
I: The Meath or something?
R: No, no, it was, Jes I used to go to school opposite it. Emm, when I got in there within, I got, I think it was 4 or 6 weeks. Now and I had no money, the government wouldn't do it, or they did all right in the end but and I think in about I was out after 4, 4 weeks.
I: And your GP...
R: He seems to have, he has this ... (pause) He seems to have this thing where he'll get you in somewhere.
I: He knows people?
R: Mmm, yeah, yeah. And I was up there in, oh there was something wrong with me, and he set me up. I walked in and you know, said the doctor after he told me and ah yes come on, and it was a Wednesday and I said they're would be nobody there and when I went in the place was packed, in the outside or something like that, ah Jesus if thy don't come to me quick I'm going and I got in... (pause)
I: Was this in ------ hospital?
R: No this is in N-----. In N----- and your man come in and he went to the doctor that's Dr. M--------'s patient you know swish, done. And he never, I'll tell you this, I never pay him. I never pay him, no (laughs).
I: Do you not get a medical card now, being over 70?
R: No, I don't know, maybe I will.
I: Automatically get one when you reach 70, yeah.

R: Oh great. It wouldn't make any difference because I didn't pay him anyhow (laughs).
I: And he still gives you a good service and you don't pay him?
R: Yeah. And at Christmas, on New Years Eve he was in the pub, and we were in the pub and I just remember thanks very much for everything you don't worry I'll look after you. Because when he came down to Kill, that's where his thing was I heard them talking about him you know, ah Jesus he's no use and all that sort of thing, he had very few people you know. And when I got the bypass you know if anybody said to me about him says I you're wrong, he's a good doctor, he's great, ah not at all, how do you think I got this. And there was a friend of mine she used to clean for him, and she must have told him what I said that he was a great doctor that's the only think I can.
I: You haven't got a bill since anyway (both laugh).
R: And when Margaret goes down with me, she pays him (laughs) and I say fuckin' Jesus what did you do that for?I never pay him (laughs).
I: Has anybody been up to the house, like an Occupational therapist or anybody like that?
R: No.
I: You're getting around fine on your feet? Your mobility is fine and you're not unsteady or anything like that?
R: I think it happened once or twice you know, maybe that's after having a few pints you know (laughs) I'm not too cure. But when I go to the pub now it would only be, I go out at half nine at the weekend eh so, no half ten and they close at half twelve, so if, I might have four or five pints you know. Some of the same.
I: Would you ever have a drink in the house here?
R: Oh yeah, when we come home, we'd have a vodka (laughs).
I: Do you attend a day centre at all or a retirement group?
R: No.
I: And would you be interested in attending anything like that?
R: I'm not a joiner, but that's not to say I wouldn't go.
I: Were you ever a member of any groups or clubs like?
R: Ah yeah.
I: Can you tell me about that?
R: I was in the GAA down below in Kill and emm, I used to play golf, a club now it wasn't a... (pause). I wasn't belonged to a club but you know, you know when 12 or 14 fells go to you know... (pause).
I: Do you miss that? Would you like to continue doing stuff like that?
R: I couldn't do it because the going up and down hills and all. And I'd never be able to get up the hills.
I: Are you driving at the moment?
R: No I leave it all to Margaret.
I: How do you find that?
R: Great (Laughs).
I: Do you really? And do you feel you're still independent?
R: Independent?
I: Yeah.
R: I think Margaret takes over a little bit you know, she would come home with trousers and Jesus I don't want the bloody thing, that sort of thing.
I: Do you miss it?

R: Not at all. I often say now if I was still working in Aer Lingus and I had a company car I'd give it up. I'd give it up, I listen to them in the morning from half seven and this place, that place and all, sure the whole place is clogged up.
I: Did you ever contact the Alzheimer's Society or anything like that?
R: Never even heard of them.
I: OK and is there any activities that you're not able to do that you would like to be able to do still?
R: Outside the, outside the garden I don't do anything. I don't do anything. Maybe there is, there is things you can play you know like snooker and that but I, I never liked them. There was a good, there still is a good bowling thing in... (pause)
I: Would you be interested?
R: Ah I didn't like some of the people there you know, you do something and they jump on you.
I: OK and is there any significant problem you face on a regular basis because of your memory problem?
R: I suppose the only think I can say is that you can't remember. That's' the only thing and the little things that you put there and you can't find them.
I: Do you have any future fears, fears about the future?
R: No, I don't think I would but I would fear for Margaret. Well let me put it this way you know, she works and ya, I, I, I (sighs) there was a fella in trouble with a company and Margaret worked for him and she asked me for money to ... (pause)

(The telephone rings, respondent goes to answer it, he then leaves to pop into a neighbour).

R: I'm just going over there, he wants flour, I won't be a minute (laughs).

R: That's the sort we are, I want something they'll give it to me and then... (pause)
I: I'm just on the last section now and it's just about what the State can do for older people. Are you getting enough at the moment?
R: Nothing except a pension. All right, I go to the hospital, I have to go up and give them 160 but emm, I really don't, I really don't, they don't worry about the ... (pause) pensioners and all that. All right they give you, I get 90 or something but that's as far as they do.
I: What do you think they should do?
R: Phew I think, I could be ... (pause) I think half of them shouldn't be in there, now I don't know what the... (pause) they're not if they were in a company they would be thrown out. But if you're thinking what can they do for me or something like that they wouldn't know how to do it. They wouldn't know how to do it.
I: Are you able to get in and out to N----- [the local town] if you wanted to go to the shops or anything like that?
R: No. No, I can't because there is a bit of a hill there coming up and especially in the winter. In the winter it's different from the summer. I can be out there all day but in the, in the winter, I can't understand it's ... (pause) The cold comes in through your head, it really does. And ... (pause) you just have to come in you know, even if there is a

dry day or something like that you know. But that's about all. I have no sighs about it at all.
I: OK and the last question, has your attitude towards memory loss changed since you developed eh the problem yourself?
R: I just don't know.
I: You didn't think about it before possibly?
R: I don't know, I don't know I don't get annoyed, sometimes I do when the words won't come out.
I: Is there a history of memory problems in your family or anything like that?
R: Oh I don't think so, my mother was a sharp as a tack, and Margaret always said you're like your mother you won't spend a penny (laughs).
I: Is there anything you'd like to add before we finish up?
R: I can answer kind of .... (pause) I can answer questions but I can't, if you asked me something I'd say something but I can't say it myself it won't come.
I: That's OK. What I might do Mr. Murphy if it's OK with you I might call next week.

(End of interview spent organising the follow-up interview).

I: Do you want me to get any information for you or anything?
R: I wouldn't know what information to look for. It's one of these things you know that you know nothing about it.
I: I have a booklet just on memory problems and some techniques you can put in to help you.
R: Do they work?
I: Some of them do. So I can bring that down with me next week.
R: Will ya?
I: Yeah