

“I’m struggling but I’m not suffering”

The lived experience of persons with young onset dementia in Ireland:

An Interpretative Phenomenological Analysis

by

Vanessa Moore

Thesis submitted to the School of Social Work and Social Policy

Trinity College Dublin

for the degree of Doctor of Philosophy

March 2021

Supervised by Professor Virpi Timonen

Declaration

I declare that this thesis has not been submitted as an exercise for a degree at this or any other university and it is entirely my own work.

I agree to deposit this thesis in the University's open access institutional repository or allow the Library to do so on my behalf, subject to Irish Copyright Legislation and Trinity College Library conditions of use and acknowledgement.

Signed:

Summary: “I’m struggling but I’m not suffering” The lived experience of persons with young onset dementia in Ireland: An Interpretative Phenomenological Analysis

This PhD thesis is an exploration of the lived experiences of persons with young onset dementia (YOD) in Ireland. YOD is the term used for dementia in persons under 65 years of age, an arbitrary cut-off point with no real medical basis, but rather a reflection of the societal start of ‘old age’. While the aetiology does not differ much, persons with YOD dementia generally have different experiences and needs compared to older persons with dementia. People with YOD tend to be physically stronger, have more energy, and are often in employment. They may still have major financial responsibilities such as a mortgage, and any children they have may be young and still in a position of dependence. In Ireland, only a handful of studies have been carried out in relation to persons with YOD; it was therefore my aim to explore, and hear in their own voice, the lived experience of persons with YOD in Ireland.

I decided that the best approach to explore this lived experience would be a qualitative study guided by constructivist principles; meaning is constructed by an individual engaging with the world, and the individual interpreting the meaning cannot describe or interpret meaning in isolation from their conscious being experiencing it. To maintain the focus on the experience of the individual, and how they interpreted their experience, I opted for Interpretative Phenomenological Analysis (IPA) as my methodology. I did this to maximise emphasis on what phenomenology calls the ‘object’, the phenomenon, which in this thesis was YOD; and how the individual’s experience of this was part of their lived process, unique to the individual’s relationship with the world. A researcher using IPA methodology adopts an interpretative stance, trying to understand the individual’s attempt to make meaning of their experience. Idiography - being concerned with the particular - is central to IPA as the particular signifies a focus on detail and depth of analysis. Another central strand of IPA is that of hermeneutics, the theory of interpretation. Hermeneutics outlines the relationship with the part and the whole – to understand any part, you look at the whole, and to understand the whole, you look at the part. IPA provides a methodology that is concerned with details, but also looks at how a phenomenon is understood and experienced by a specific individual in a particular context.

I approached gatekeepers for the recruitment of participants. Using purposive sampling to approach potential participants, ultimately ten persons with YOD were willing to participate in the study. I carried out in-depth, semi-structured qualitative interviews with the ten participants to collect data. In five of the interviews, the spouse or partner of the participant

was present. The interviews were recorded, transcribed verbatim by the researcher, and the transcripts used as a basis for coding the data and developing themes. These were then organised into main themes and sub-themes, and overarching themes eventually developed into the three main strands of findings. Throughout the analytical process, I also continuously reflected on my own biographical presence in the research, and the preconceptions and biases that I was bringing.

The findings from the interviews were divided into three chapters: pathway to diagnosis and disclosure of YOD; experiences of living with YOD; and the personal sphere and YOD. The first Findings chapter details how the participants struggled with symptoms they could not understand, and how they generally had to visit their GP a number of times before being referred to a specialist, who in turn often did not know how to deal with their issues. While a few participants had good experiences with knowledgeable GPs who referred them directly to a Memory Clinic, for many the pathway to care was confused, unclear and unsatisfactory. Likewise, in terms of disclosure of diagnosis, the experiences differed, with some participants being given their diagnosis in a respectful and appropriate way, but others being told in a dismissive and matter-of-fact way with no follow-up or help, which had a very negative effect on some participants.

The second Findings chapter, on living with YOD, showed that the almost total lack of services was a major issue for many participants. From matters as simple as having difficulties getting a medical card, to no access to cognitive rehabilitation or practical guidelines on how to live with YOD, to the near complete absence of suitable day care services or even support groups, the participants reported that services were inadequate or unavailable. In addition, the stigma that surrounds YOD and dementia in general was also a major finding in the study, with the participants sharing how stigma affected them and, in some cases, what they did to combat the stigma. In the final Findings chapter, issues around employment were explored, as a number of the participants had ceased employment in the lead-up to diagnosis when the problems they were experiencing meant that work was becoming increasingly difficult. In addition, the worry around children and how the illness would affect them was a constant and very real concern for the participants with children. Finally, the ability of a number of the participants to still live well and have a good quality of life despite their illness was a finding that was unforeseen, yet very important.

To conclude, the findings of this thesis exploring the lived experiences of persons with YOD in Ireland showed that the pathways to care and the interactions with health care professionals

were in need of improvement and better structure. Specific supports and services, chronically underfunded and ignored despite over 20 years of highlighting of the issue, are urgently needed and would improve the quality of life of the person with YOD and their ability to stay at home longer. Finally, the stigma around YOD must be challenged, and to show that while living with YOD may be a struggle, it does not have to mean suffering, and that living well with the illness is possible.

Acknowledgements

My first, and my deepest, thank you goes to the ten participants of the study. They told their stories and experiences with great generosity and spirit, and shared with me some of their most difficult moments and most private thoughts. Not only did they show immense kindness in their contributions, but also invited me into their home, offered me tea, introduced me to their families, made more tea, baked homemade scones, and made yet more tea – all participants were exceptionally welcoming in every way. It was a privilege to meet them and listen to them, and I am extremely grateful for their contributions and selflessness. Without them, this study would not have been possible.

A note of thanks also to the gatekeepers. Their professionalism and cooperation was much appreciated, and they went out of their way to be helpful and took great interest in the study.

I want to say a heartfelt and large *kiitos paljon* to my supervisor, Professor Virpi Timonen. She helped me in many ways, primarily by being very understanding, patient, kind and supportive, and believed in me and my ability to complete the PhD at all stages of the process. She was always available and always helpful, not least by providing clear, effective, feedback! She was especially supportive when I had my son, Eskil, and put me at ease in relation to taking full (and then more) maternity leave, which was very appreciated. Her vast knowledge, gently guiding hand, and above all, patience, helped me no end.

Special thanks to the School of Social Work and Social Policy, TCD for their support and for funding this PhD. Also in TCD, I would like to thank Dr Mary Sheridan, Trish Murphy, and Helen Thornbury for their support. Thank you to the DSIDC in St James's Hospital, especially Matthew Gibb for always being so kind.

A special thanks also to Professor Suzanne Cahill. It was Suzanne who first introduced me to the area of dementia, and her passion was contagious – through her enthusiasm and support I learnt so much about dementia, and it gave me the confidence and motivation to pursue a PhD. Since I first got to know Suzanne in 2010 she has been a supervisor, boss, mentor, and friend, and I am very grateful to her in every way.

Throughout the process of writing this PhD, I have been very lucky to have some great peer support. Thank you to Maria Pierce, Ana Diaz Ponce, Andrea Bobersky, Caroline Forsyth and Martha Doyle in the Living with Dementia Programme, TCD. Thanks also to SORCHA O'KEEFFE. Special thanks to my enthusiastic, one-woman, transatlantic support team, Alana Smith Walsh.

I could not have completed this PhD without the support of my family. Thanks in particular to my sister, Rebecca Moore, and especially to Declan and Eskil for the support, mamma hugs and all the cups of tea! But the biggest thanks goes to my parents, Stephen and Agneta Moore – without their support, this PhD would not have been possible.

This PhD is dedicated to the memory of Siobhaín O’Doherty, MSc 2010 classmate, and SPHeRE PhD student in Maynooth University when she died in 2017.

LIST OF ABBREVIATIONS

AD – Alzheimer’s Disease

ASI – Alzheimer Society of Ireland

CRPD – United Nations Convention on the Rights of Persons with Disabilities

FTD – Frontotemporal Dementia

GP – General Practitioner

HSE – Health Service Executive

IPA – Interpretative Phenomenological Analysis

LOD – Late Onset Dementia

MMSE – Mini Mental State Exam

YOD – Young Onset Dementia

LIST OF TABLES

Table One – Participants p. 65

TABLE OF CONTENTS

DECLARATION	2
SUMMARY	3
ACKNOWLEDGEMENTS	6
LIST OF ABBREVIATIONS	8
LIST OF TABLES	8
CHAPTER ONE – INTRODUCTION	12
1.1 Background	12
1.2 Research rationale	13
1.3 The researcher in context	14
1.4 Thesis structure	14
CHAPTER TWO – LITERATURE REVIEW	17
2.1 Introduction	17
2.2 Method of review	18
2.3 Models of understanding dementia	19
2.3.1 Biomedical model	20
2.3.2 Personhood model	20
2.3.3 Citizenship model	22
2.3.4 Human rights-based model	23
2.4 Healthcare-related influences of young onset dementia	25
2.4.1 Definition and prevalence	25
2.4.2 Diagnosis	27
2.5. Life course influences of young onset dementia	29
2.5.1 Employment	30
2.5.2 Children	32
2.5.3 Caregiving	33
2.5.4 Living well with young onset dementia	35
2.6 Societal influences of young onset dementia	37
2.6.1 Stigma	38
2.6.2 Provision of services and supports	40
2.7 Irish context	43

2.7.1 Development of dementia policy in Ireland	43
2.7.2 Young onset dementia in the Irish context	47
2.8 Summary	49
 CHAPTER THREE – METHODOLOGY AND METHODS	 50
3.1 Introduction	50
3.2 Research design	50
3.2.1 Qualitative research strategy: Constructivism and phenomenology	50
3.2.2 Interpretative phenomenological analysis	52
3.3 Ethical considerations	54
3.3.1 Including a person with dementia in research	54
3.3.2 Informed consent	55
3.3.3 Interviewing a person with dementia	56
3.3.4 Using the word dementia	57
3.3.5 Researcher reflexivity	58
3.3.6 Ethical approval	61
3.4 Recruitment	61
3.4.1 Sampling	61
3.4.2 Inclusion criteria	62
3.4.3 Gatekeepers	62
3.5 Data collection	63
3.5.1 In-depth interviews	63
3.5.2 Participants	64
3.5.3 Excluded participants	66
3.5.4 Levels of insight and ability of participants	67
3.6 Data analysis	68
 CHAPTER FOUR – FINDINGS AND DISCUSSION I: PATHWAY TO DIAGNOSIS AND DISCLOSURE OF YOUNG ONSET DEMENTIA	 72
4.1 Introduction	72
4.2 Symptoms	72
4.3 Interaction with medical world	76
4.4 Disclosure and aftermath	83
4.5 Discussion and concluding thoughts	93
 CHAPTER FIVE – FINDINGS AND DISCUSSION II: EXPERIENCES OF LIVING WITH YOUNG ONSET DEMENTIA	 97
5.1 Introduction	97

Moore, V	2021
5.2 Stigma	97
5.3 Services, or lack thereof	106
5.4 Discussion and concluding thoughts	112
CHAPTER SIX – FINDINGS AND DISCUSSION III: PERSONAL SPHERE AND YOUNG ONSET DEMENTIA	117
6.1 Introduction	117
6.2 Employment	117
6.3 Children	124
6.4 Living well with dementia	132
6.5 Discussion and concluding thoughts	148
CHAPTER SEVEN – CONCLUSION	155
7.1 Introduction	155
7.2 Original contribution of thesis	155
7.3 Future Research and Recommendations	157
7.3.1 Pathways to care and health service interactions	157
7.3.2 Supports and services	158
7.3.3 Challenging stigma to live well	161
7.4 Lessons learnt	164
7.5 Limitations of the study	166
7.6 Concluding thoughts	167
BIBLIOGRAPHY	169
APPENDIX A – PARTICIPANT INFORMATION SHEET	179
APPENDIX B – CONSENT FORM	181
APPENDIX C – INTERVIEW SCHEDULE	182

CHAPTER ONE – INTRODUCTION

1.1 Background

Dementia is an umbrella term for diseases of the brain with similar characteristics, which affect a person's cognitive functions. Generally it is a progressive illness and causes intellectual and physical impairments; the most common form of dementia is Alzheimer's disease (AD) (Cahill, 2018). The main risk factor for dementia is age, however it is important to point out that dementia is not an inevitable or normal part of ageing (World Health Organisation, 2017). Dementia is one of the major causes of disability in later life, and the prevalence doubles in every five-year increment in age after 65 years of age (World Health Organisation, 2012).

Dementia does not exclusively affect older people. Young onset dementia (YOD), defined as the onset of symptoms of dementia before the person is 65 years of age, accounts for up to 9% of cases of dementia (World Health Organisation, 2012). This group faces different challenges to those with late onset dementia (LOD); they may still be in employment, have financial obligations such as mortgages, and often have children under 18, or children who are young adults but still dependent on their parents. Due to their age they are often physically strong and fit, and have higher energy levels. Because of the age spectrum, their families may have different support needs than families of an older person with dementia. In short, while the diseases may be largely similar, the needs and supports of persons with YOD are different.

This thesis is an exploration of the experiences of persons with YOD of accessing care in Ireland, and their lived experience of life with YOD. The topic was chosen in order to find out more about the situation and lived experiences of this largely overlooked group in an Irish context. One estimate suggests that approximately 8.6% of persons with dementia in Ireland are under 65 years old, nearly 3,600 people (Cahill et al., 2012). Compared to persons with LOD, relatively little research exists about this group, and their needs.

This study therefore set out to investigate how persons with YOD had navigated their pathways to care and interactions with the health care system, as well as their experiences of services. The study provides an extensive account of living with YOD in Ireland, both in terms of the effect of the illness on the person's employment, family situation, and children, but also how issues such as stigma and lack of services affected the participants' lives, and how constructive ways of coping with YOD helped create a new, albeit different, way of living, and living well, with YOD.

1.2 Research rationale

YOD is getting more attention in research over the last decade, however in many ways it is still the 'poor relation' of the dementia family. In Ireland, there has been limited research carried out relating to YOD, and the voices and experiences of those with YOD have largely remained unheard, apart from a few exceptions. I therefore wanted this PhD to focus specifically on persons with YOD, to explore their experiences in relation to the health care system and social care system, as services for people with YOD are especially poor. I also felt that it was imperative to include the person with YOD in the research, rather than relying on proxy accounts or family members or support persons. The involvement of the person with dementia in research has not always been a given, due to outdated beliefs that the person cannot express themselves, or that a person with dementia should be protected from any disruption. However, in line with the phrase often used by disability and other activists, "*nothing about us without us*", I felt that would not be possible to conduct an exploratory study of the experiences of persons with YOD lived without including their individual accounts.

The study was therefore designed as a qualitative study; this was the most suitable type of research method for a thesis of an exploratory nature. I decided that the best way of constructing the research and of compiling and analysing the data was by using a phenomenological approach, and therefore I chose Interpretative Phenomenological Analysis (IPA) as the methodology. In-depth interviews with persons with YOD, together with a family member or support person if the person with YOD preferred it, were carried out to collect the data, which was then analysed and organised into themes and findings. The rich findings that came out of the interviews make a novel and unique contribution to the knowledge base of the experiences of people with YOD in Ireland.

The data emanating from this PhD study shows that while the healthcare experience of those interviewed was generally not optimal, and there was a limited uptake of services, mainly because of the lack of any appropriate services, the lived experience of YOD was multifaceted and intricate. While participants expressed feelings of loss and sadness in relation to for example cessation of employment, or expressed concern and worry for their children and how the illness would affect them, their stories also revealed lives that were still lived in a meaningful way, using the support of family and extended support circles such as friends and community to help them cope. While it is in no way the intention of this study to minimise or trivialise the effect of a dementia diagnosis, or the difficulties of living with dementia, the findings nevertheless indicate that with the right support, it is still possible to live successfully, albeit differently, with YOD.

1.3 The researcher in context

My original interest in the area of dementia came through learning more about the illness during a work placement at Trinity College Dublin's Living with Dementia programme (LiD) as part of my MSc in Applied Social Research. Up until then, I had very limited awareness of dementia, and had no family or friends who had experienced the illness. Influenced by my time in LiD, my MSc dissertation was a comparative study of the attitudes and experiences of Swedish and Irish General Practitioners in diagnosing and disclosing dementia. I subsequently worked as a research assistant at LiD for nearly two years, being exposed to all things dementia, and it was during this time that my interest in YOD was sparked. The paucity of Irish research on the topic, and the fact that such a distinct group had virtually no specific services, seemed irrational and I wanted to find out more about this group: what were their experiences living with YOD in Ireland, and how did they view their own situation.

I therefore chose to focus on this group in particular when I started my PhD, and to investigate how they perceived the health care system and the social care system, what their lived experiences were, and above all, to hear their voice. Through their great generosity, the participants in the study shared nuanced and textured narratives of their experiences and their lives with me, providing a valuable contribution to knowledge of the area in general, and of the Irish context in particular.

1.4 Thesis structure

This thesis is divided into seven chapters. The chapters are preceded by a list of abbreviations, and are followed by a bibliography and appendices.

This introduction makes up Chapter One. It is followed by *Chapter Two: Literature Review*. This chapter opens with a description of the type of review and how the searches were carried out. It then moves on to analysing past and present concepts and models of dementia, and how they facilitate the understanding of dementia and put research into context. The review then explains the differences between YOD and LOD, and looks at the prevalence, aetiology, and diagnosis of the YOD. Next the literature relating to a number of select areas of living with YOD is analysed; these areas include employment, children, caregiving, living well with YOD, stigma, and services. The chapter finishes with an overview of dementia in Ireland, where the development of dementia policy in Ireland is traced, and YOD in Ireland is put into context.

Chapter Three: Methodology and methods describes the research design and epistemological justification for adopting IPA as the methodology for the study. It explains the ethical considerations of carrying out the research, including areas such as consent, and including and interviewing a person with dementia in research. It then outlines the methods of recruitment, sampling, inclusion criteria, and data collection. It also gives a detailed description of the participants. Finally, the practical aspects and steps taken in analysing the data are discussed.

The next three chapters present and analyse the findings of the research. The findings are presented in three thematic areas, tracing the participants' experiences of YOD: healthcare and disclosure of diagnosis, experiences of living with YOD, and the personal sphere of YOD. Each chapter finishes with a section named *Discussion and concluding thoughts*, which analyses the findings in further detail.

Chapter Four: Findings and discussion I – Pathways to diagnosis and disclosure of young onset dementia introduces the participants of the study as they describe their first symptoms of YOD, and their decision to seek medical help. It goes on to detail their interaction with health care services, and concludes with the disclosure of a diagnosis of YOD, how this affected the participants, and how they dealt with the aftermath.

Chapter Five: Findings and discussion II – Experiences of living with young onset dementia presents findings relating to practical aspects of living with YOD, in this case stigma and service use. The omnipresence of stigma, and how it affected the participants' decision-making, disclosure of diagnosis to family and friends, and their day-to-day life is discussed, together with the nihilism and bleakness that is a consequence of stigma. The second part of the chapter looks at the services available to the participants, and what if any experience they had of using or looking for services. What services they would like to have, and how the general lack of services affects them, is also discussed.

Chapter Six – Findings and discussion III – The personal sphere and young onset dementia details the participants' exploration of the way their personal lives have been affected by their illness. Areas like the disruption and cessation of employment as a result of YOD, and the deep and constant concern and worry around the effect of the illness on children is discussed. The final part of the chapter looks at everyday life with YOD, and the ways in which participants live day-to-day, how they make sense of the illness and the future, and how participants were able to live differently, but well, with YOD.

The final chapter in this thesis is *Chapter Seven – Conclusion*. This chapter summarises the findings and analyses the data on a broader level, concluding with recommendations for future research. It also outlines the original contribution of this thesis.

CHAPTER TWO – LITERATURE REVIEW

2.1 Introduction

This chapter aims to review some of the existing literature relating to people with YOD and their experiences. The IPA methodology used in this thesis stresses the importance of maintaining flexibility and approaching data analysis without any preconceived ideas, to avoid interpreting the data based on pre-determined associations from the literature. It is nevertheless accepted that the researcher, regardless of previous knowledge of the area, will want to be aware of the current literature and issues (Brocki & Wearden, 2006). A short initial review of the literature is therefore generally carried out before data collection starts, and then updated in the writing up process.

The aim of the literature review is to introduce the field of study, to be evaluative of the literature included, and to use it to provide context of the chosen topic of study, as opposed to generating a theory-driven or overarching framework (Brocki & Wearden, 2006; Smith et al., 2009). In summary, the purpose of a literature review within IPA methodology is not to disregard all literature until after data collection and analysis, nor is it to assemble a fully representative, systemic overarching body of works in support of a specific theoretical framework; rather, it introduces and analyses the topic and relevant concepts in literature that provide narrative and context (Smith et al., 2009).

The chapter will begin by outlining a number of models of understanding dementia, including key concepts and theories. These give a contextual understanding of what the views of dementia have been, and how these have been re-framed in different ways over the last two decades in order to put the person with dementia at the centre, and fully respect their autonomy and rights.

The chapter will then move on to issues more specifically relating to YOD. A diagnosis of dementia at any age is momentous, however the life stage of a younger person constitutes a unique and particular context. Specific challenges include for example young children still living at home, or young adult children that are still dependent; the person with YOD may still be in employment, as well as the person caring for them, most often the spouse; and personal financial obligations may include mortgage payments or tuition for children (Chaston, 2011; Chemali et al., 2012; Hoppe, 2019).

Other issues that concern persons with YOD that also are part of this chapter include difficulties of getting a correct diagnosis of YOD; the lack of specialist provision of services for

those with YOD and the inappropriate incorporation of services for YOD with older people's care; the task of caring for a person with YOD and the lack of supports; the high level of stigma surrounding YOD; and the ability to, despite all the issues, live well with YOD (Clemerson et al., 2014; Draper & Withall, 2016; Roach et al., 2008; Tolhurst et al., 2014). These topics will all be discussed in the context of the literature. As this study is concerned with the experiences of people with YOD in Ireland specifically, the chapter will finish with an overview of dementia policy within the Irish context.

2.2 Method of review

The review carried out was a narrative literature review: the breadth of search method offered by a narrative review best suited the chosen topic for this exploratory study. A narrative review enables the researcher to approach the topic with a wide scope, as well as with flexibility to deal with the evolving knowledge and concepts that are encountered (Byrne, 2016). Approaching the searches topically, I paid specific attention to research on YOD that involved the individual with YOD, or that viewed the topic through a contextualised framework such as for example personhood. This type of literature review also helps identify gaps in the literature, as well as contributing to the focus of the research, and being useful in gathering and synthesising the literature (Baker, 2016).

A search of the literature was conducted between September 2012 and June 2013, and then again in 2019 and 2020. Databases searched included Web of Science, Psych INFO, PubMed, and CINAHL. Searches were also done for grey literature, reports, policy documents and other relevant publications. Search terms used in a mix of combinations and keywords such as 'young onset dementia', 'early onset dementia', 'dementia', 'Alzheimer*', 'employment', 'financial', 'children', 'personhood', 'carer', 'caring', 'diagnosis', 'stigma'.

As there is a lot of material relating to dementia, more generic searches would bring up many hits; for example, a Web of Science search on ['young onset dementia' OR 'early onset dementia'] would bring up over 1000 hits. However, these were the preferred search terms as doing searches using the term "Alzheimer*", even with specific keywords, bring up an overwhelming number of hits, the majority of which are medical. Even when searching specifically for "early onset Alzheimer*", the hit levels would be nearly double that of using the term "dementia" instead.

When doing literature searches, I combined the various search terms mentioned above, and generally worked my way through the result list (using “Relevance” as the sorting options, as opposed to date which is the default in some search engines) until the results were no longer relevant, or had become solely medical. When combining [‘young onset dementia’ OR ‘early onset dementia’] with keywords such as children, or stigma, or employment, the results would vary from a handful up to 300, however the average was around 150 depending on the search engine.

The only search restriction entered into the search engines was to restrict the language to English or Swedish language publications. However, a number of ‘implicit’ restrictions were used in choosing what literature to consult. Because of my own study design, I focused more on studies that were carried out using qualitative research methods, and generally did not peruse medical or clinical studies. I also reviewed research that employed a specific conceptual model of approaching dementia, where relevant. I concentrated mainly, but not exclusively, on research carried out in Anglo-Saxon or Nordic settings, as these are the systems I am most familiar with; in addition, most research was welfare-state based, again due to researcher familiarity, but also as it reflected the participants’ own health care system to a certain extent. I also tended to consult literature that was not more than 10-15 years old, as YOD is quite a recent area and is developing rapidly. However, I felt it was important not to disregard older literature through applying a search filter limiting results to 10 or 15 years, as older literature can provide great perspective, or indeed present theories that went on to become pioneering in the field.

The inclusion of some form of framing of how dementia was approached and understood was very important for this narrative literature review, as such contextualising gives a fuller understanding of the research, its purpose, and its implications. This next section further describes such contextual framing, and gives an overview of dementia models and the development of some of the most relevant ones.

2.3 Models of understanding dementia

How researching issues around dementia is approached, and how it is conceptualised, will have a great impact on framing any research undertaken, and how issues around needs, policy, practice, and research are approached (Cahill, 2018). The context around dementia has been and is continuously evolving, and numerous different frameworks theorise how to best approach and understand the illness. A conceptual framework is also helpful as it assists with

using concepts or models from various theories and findings to guide research, and it can give foundations and rationale for the direction of the research (Green, 2014).

As the understanding of dementia has developed, the previously dominant biomedical model is being challenged with a number of theories looking at the illness and its effects in a more holistic and person-centred way. Such models of understanding dementia, which present a framework through which the illness can be viewed, introduce concepts which can be used to assist insight and knowledge (Cahill, 2018). This section will briefly look at the still-present biomedical model, followed by the introduction of the concept of personhood, citizenship model, and finally a human-rights-based approach to dementia.

2.3.1 Biomedical model

The biomedical model reduces dementia solely to an illness where parts of the brain are malfunctioning, causing difficulties; it essentially excludes other perspectives or approaches on the basis that the person is their organic body only, and becomes synonymous with the illness (Cheston & Bender, 1999). By focusing only on the 'diseased brain', and not on the person to whom the brain belongs, the individual is left out and the central theme becomes that of deficits – of what the person can no longer do – as opposed to abilities that are retained. The biomedical model largely objectifies the person with dementia, seeks the opinions of the person's family rather than the person, and does not involve the person with dementia in decisions about their care or their everyday life (Bartlett & Martin, 2002). In short, the person with dementia is seen as "...a merely biological problem, to be solved by some kind of technical intervention" (Kitwood, 1997, p. 44).

In the context of dementia services, the biomedical model has been the basis for often paternalistic and protective practices towards persons with dementia, instead of an approach supporting empowerment and enablement (Cahill, 2018). While the biomedical model has been and is challenged continuously, it still strongly shapes both the social and professional perception of dementia (Tolhurst et al., 2014) despite its many obvious shortcomings. Shakespeare and colleagues go as far as describing dementia as still being 'trapped' within the dominant medical model (Shakespeare et al., 2019).

2.3.2 Personhood model

One of the main early challengers to the biomedical model was the Bradford Dementia Group in the UK, where together with his colleagues, Tom Kitwood spearheaded the movement to

find a different and more person-centred conceptualisation of dementia, where the person was to be seen first and the dementia second (Clarke & Keady, 2002). Kitwood's 1997 seminal text, *Dementia Reconsidered*, outlined the need for the thinking around dementia to change. He argued that personhood, which he defined as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being" (p. 8), is what should be the defining characteristic of a person, and not their illness; persons who have dementia must be seen in their full humanity as a *person-with-dementia*, rather than a person-with-*dementia* (Kitwood, 1997a).

Kitwood also discussed the connection between the dehumanisation and 'othering' of a person with dementia, and stigma and fear, noticing that a person with dementia may spark fears of dependence, frailty, and of losing one's mind. These fears in turn trigger the defence tactic of turning the person with dementia into a 'different species', not a person in the full sense, and someone whose behaviour must be managed and controlled. Kitwood further argued that the biomedical model feeds a nihilistic view of dementia, viewing it as 'death that leaves the body behind', and a depersonalisation characterised by fear, defence, and ageism (Kitwood, 1997a).

Kitwood continued to argue that to genuinely recognise the personhood of those with dementia, a cultural transformation was needed. Both family, professional carers, and other professionals interacting with the person with dementia must respect and support the uniqueness of the person with dementia and what they have accomplished and endured; they must be committed to engage with psychological needs; and to prioritise the day-to-day existence of the person with dementia and how to maintain their personal well-being (Kitwood, 1997a). The main task of dementia care, in Kitwood's opinion, was to maintain personhood through the sensitive adaptation of a cluster of needs (attachment, comfort, identity, occupation, inclusion) in a way that accepts and adapts to the uniqueness of the individual in question (Kitwood, 1997b).

The shift in thinking offered by Kitwood and the Bradford Group was the beginning of a change in the theorising around dementia care and treatment, with the person with dementia becoming the focus of care, and service providers compelled to change outdated or ineffective care practice (Clarke & Keady, 2002). Cheston and Bender, writing in 1999, offered a critique of Kitwood's then recent work on personhood. Recognising the ground-breaking nature of his work, their take on the importance of the person with dementia was slightly wider. Like Kitwood, they believed that the central task for health and social care professionals should be

to understand the subjective world of the person who has dementia, that their experience is the main focus, and that carers' needs should be viewed not in isolation from the person with dementia but rather as part of their relationship. However, they also argued that in order to understand how people respond to the problems created by dementia, it was crucial to look beyond the person with dementia and their family, and to also consider their cultural and societal context, and the systems that impacted on them (Cheston & Bender, 1999).

O'Connor and colleagues elaborate this argument, stating that it is necessary to identify the ways in which health policies, institutional cultures and practices, and socio-cultural norms and values shape the experience of dementia, rather than simply only consider personal and interactional experiences in relation to personhood (O'Connor et al., 2007). Cahill also points out Kitwood's failure to include socio-political structures in his assessment of what impacts the experience of dementia and undermines personhood, and argues that Kitwood's apolitical approach, which analysed issues at a micro (personal) rather than a macro (political) level, can lead to ageism, sexism, disablism, and the absence of well-developed public policy on dementia (Cahill, 2018).

2.3.3 Citizenship model

The concept of personhood, while ground-breaking, was thus too narrow and restricted by its lack of political dimension; however, using personhood as a basis, the framework around how to understand dementia continued to be developed (O'Connor et al., 2007). Building on the personhood framework, the citizenship model provided another way of conceptualising dementia. Bartlett and O'Connor argued in their 2007 article that citizenship, which is associated with civil, political, and social rights, recognises that participation and inclusion in society is inevitably shaped by power dynamics.

Citizenship can be defined as a status where a person with dementia is entitled to experience freedom from discrimination, and to have full access to opportunities to participate in life (Hughes, 2019). Through the citizenship model, activities of people with dementia take on a political meaning in addition to the personal; this is an experience shared with the disability movement, which originally raised awareness of the denial of citizenship that people with disabilities experienced (Bartlett & O'Connor, 2007). A citizenship model, in contrast to personhood, focuses on issues such as social inclusion, power, and citizenship as practice (Baldwin, 2008).

Bartlett and O'Connor state that in relation to discrimination and social inequality, the process of what they call 'making the personal political' can improve the status of marginalised groups. Citizenship is not a status whereby rights are automatically attached, given benevolently to the person, but rather something individuals achieve for themselves; being a citizen is something you do, as opposed to something to strive to be (Bartlett & O'Connor, 2007). For persons with dementia, they may realise their citizenship through commencing or participating in advocacy, or being involved in research (Baldwin, 2008).

Viewing citizenship in a broader context than just civil and political rights, the social structures needed to enable people with dementia to participate in a community can be explored through the citizenship model; it can also counteract the discourses that support intentional or non-intentional but paternalistic exclusion of persons with dementia from equal participation in society (Birt et al., 2017). Citizenship is closely intertwined with the person's own existence and sense of belonging in and contributing to society, and thereby also the legal, political and social rights of citizenship are embedded in social relationships and everyday activities (Baldwin, 2008).

Criticisms of the citizenship framework have pointed out a number of shortcomings. The traditional view of citizenship, that everyone wants and should have the same rights and responsibilities, does not include an individual dimension, or take into account politics of difference; internal differences within a social group may be overlooked or ignored (Bartlett & O'Connor, 2007). Also, the emphasis on 'cognitive knowledge' and a 'hypercognitive culture' makes it more difficult to acknowledge that deteriorating abilities may limit a person's scope to exercise associated rights and practice; the citizenship approach can therefore struggle to fully recognise the essence of individuality (Bartlett & O'Connor, 2007).

2.3.4 Human rights-based model

To enable focus on the wider socio-political structures affecting persons with dementia, while at the same time allowing for the importance of individuality and the individual rights that a person with dementia has, a human rights-based model of dementia has begun to gain ground. Rooted in disability models, the human rights approach argues that dementia is a disability, and because of this, a person with dementia is entitled to each of the rights set out in the United Nations Convention on the Rights of Persons with Disabilities (CRPD). Human rights are inherent to the dignity of all persons, however as persons with a disability those with dementia have a higher risk of experiencing injustices, marginalisation and

discrimination, for example structural barriers when accessing diagnostic and post-diagnostic services, attitudinal barriers such as stigma and prejudice, their autonomy rights being overlooked, and their dignity and privacy disregarded (Cahill, 2018).

The CRPD deals with issues pertinent to those with dementia, such as access to health and community care and support; that the individual must be actively involved in decision-making when it comes to the design and delivery of their service provision and support; have a right to health without discrimination; and a right to supported decision-making in order to exercise their legal capacity (Dixon et al., 2020). The CRPD also highlights the obligations of states and other stakeholders to protect the rights of the person with dementia (World Health Organisation, 2015).

The World Health Organisation greatly supports the human rights-based approach to dementia, and details the myriad ways it should be implemented to deal with dementia as a public health issue in its 2017 *Global action plan on the public health response to dementia* (World Health Organisation, 2017). Dementia, in the context of human rights and the CRPD, highlights the diversity of disability, and also the importance of situating the individual experience of dementia within the broader social context, with self-advocacy as a core principle (Shakespeare et al., 2019).

Cahill, in her book entitled *Dementia and Human Rights*, states that a human rights-based approach to dementia, underpinned by the social model of disability, provides a framework which allows for expansion of knowledge and understanding of dementia. The human rights-based approach, she argues, supports the civil, political, social, economic and cultural rights that the individual living with dementia needs to live well, free from stigma and discrimination, to exercise decision-making, have a choice, exercise autonomy, to receive support, and to be valued and treated with dignity and respect. In all this, the voice of the person with dementia must be heard (Cahill, 2018).

The models of dementia outlined above have introduced issues around the framing of dementia in general, and the important concerns underpinning each model. As conceptualising and theorising around matters relating to dementia continues, the biomedical model is constantly challenged, and its stigmatising and paternalistic grip contradicted. As the above models show, frameworks and models of dementia are crucial to understand dementia and all its complexities (Shakespeare et al., 2019), and set the scene for the next sections of this chapter, the topical review of some of the literature relating to YOD. This review consists

of three main sections: healthcare related influences, life course influences, and societal influences on living with YOD.

2.4 Healthcare-related influences of young onset dementia

This section of the literature review focuses on the more health care-related areas of YOD. It discusses the definition of YOD, and then analyses prevalence rates both internationally and in Ireland. It concludes by examining the issues around diagnosis of YOD.

2.4.1 Definition and prevalence

The word “dementia” is derived from the Latin *demens*, meaning literally ‘without mind’ (SBU, 2008). Dementia is used as an umbrella term to describe a group of diseases characterised by a progressive and in most cases irreversible decline in the cognitive functioning of the person with dementia. The most common type of dementia is Alzheimer’s Disease, followed by vascular dementia and Lewy body dementia (O’Shea & O’Reilly, 1999). While dementia is technically a set of symptoms that can be caused by a number of different diseases, in the vast majority of cases dementia is progressive, irreversible, and causes physical and intellectual impairments (Cahill, 2018).

YOD is defined as dementia with symptom onset before the age of 65 (Draper & Withall, 2016); this specific cut-off point will be discussed in more detail later in this section. YOD is also referred to as early onset dementia (EOD), or in some more medicalised or old-fashioned texts, presenile dementia. YOD and EOD tend to be used interchangeably, however this is not optimal and can cause confusion. The Shared Interest Forum on young onset dementia of the International Psychogeriatric Association discussed the issue at length, and found that while early onset dementia is the term more widely used, it is also used to mean early stage dementia; they therefore agreed on using solely the term Young Onset Dementia (Koopmans & Rosness, 2014). Following this logic, YOD is the term used throughout this study.

While the illnesses that cause YOD are broadly similar to those of dementia in later life, some differences exist. As with LOD, the most common illness causing dementia in those under 65 is Alzheimer’s Disease, followed by vascular dementia and frontotemporal dementia (FTD). Younger people are more likely to have rarer forms of dementia, and other diseases common in YOD include Lewy body dementia, Pick’s disease, alcohol-related dementia, traumatic brain injury, Creutzfeldt-Jacob disease, Huntington’s Disease, Motor Neuron Disease, and chronic traumatic encephalopathy (Hoppe, 2019; Kuruppu & Matthews, 2013; Teles Vieira et al.,

2013). While AD is the most common cause of YOD, it still only accounts for 34% of YOD, compared to about 80% of LOD (Kuruppu & Matthews, 2013).

The aetiology of YOD does not always fit the general symptoms of memory loss of LOD, but often includes psychiatric manifestations, behavioural changes, depression and psychosis (Kuruppu & Matthews, 2013). Symptoms of YOD tend to be more neuropsychiatric rather than cognitive, as is typical with FTD; symptoms of unusual behaviours, emotional problems, and disruptive changes as opposed to the 'traditional' symptom of memory loss and confusion make misdiagnosis common (Pang & Lee, 2019; Van Vliet et al., 2013). More men than women have YOD, and persons with YOD dementia tend to live longer with the disease, and also tend to remain living at home for longer than those with LOD (Novek et al., 2016), putting extra pressure on the carer. Pharmacological treatment of YOD roughly follows that of LOD, in that cholinesterase inhibitors offer symptomatic benefit in AD but do not stop the progression of the illness (Kuruppu & Matthews, 2013). Any other medication use has little effect on behaviour or disease symptomology, and runs the risk of escalating to poly-pharmacy with little or no benefit (Chemali et al., 2012).

While these issues point to some differences between YOD and LOD, there are nevertheless very limited neurobiological distinctions in relation to age (Draper & Withall, 2016; Tolhurst et al., 2014). The general consensus is that the cut-off point of 65 years old as a distinction between YOD and LOD is completely arbitrary, and relating to the conventional line of the employment and retirement age but with no specific biological significance. In fact, there are a range of disease features of dementia that cross this arbitrary age divide (Draper & Withall, 2016; Koopmans & Rosness, 2014; Lambert et al., 2014; Rossor et al., 2010; Teles Vieira et al., 2013; Tolhurst et al., 2014). The Diagnostic and Statistical Manual of Mental Disorders IV of the American Psychiatric Association gives no distinction relating to age for the different types of dementia. For Alzheimer's Disease, it does mention the subtypes 'Alzheimer's disease with early onset' and 'Alzheimer's disease with late onset' but states that the distinction is based on age at the time of diagnosis, and also clarifies that: "The diagnostic code depends entirely on the presence or absence of a clinically significant behavioural disturbance and not whether the dementia is of early versus late onset" (Tolhurst et al., 2014, p. 7).

Epidemiological studies about the prevalence of young onset dementia tend to be scarce, and the ones that do exist are heterogenous in their design and purpose; comparison of results is therefore generally difficult, meaning that a wide range of prevalence quotes exist for YOD (Lambert et al., 2014; Teles Vieira et al., 2013). For example, estimates of the prevalence of

YOD in those under 65 years of age range from 38 to 420 cases per 100,000 (Werner et al., 2019), whereas Hoppe (2019) states that between 0 and 700 per 100,000 people have YOD. Johannessen and colleagues (Johannessen et al., 2016b) estimate that 5% of all people with dementia are under 65 years, as do Bakker and colleagues (Bakker et al., 2010). Mayrhofer and colleagues (Mayrhofer et al., 2018) quote a figure of 42,500 persons in the United Kingdom living with YOD. Generally, however, it is estimated that between 2% and 10% of all cases of dementia start before the age of 65 (World Health Organisation, 2012), and the incidence increases with age (Teles Vieira et al., 2013).

The number of people with dementia in Ireland is estimated to be around 55,000, with approximately 4,200 of those having young onset dementia (O'Shea & Carney, 2016). A recent study on the prevalence of dementia in Ireland, carried out using international evidence on prevalence and incidence patterns, has provided a wide range of estimates. This is due to two factors: the afore-mentioned uncertainty in relation to the epidemiology of dementia internationally, and the fact that these estimates have to be used as there are no Irish local or national prevalence studies (Pierse et al., 2019).

Pierse and colleagues therefore estimate that the number of people with dementia in Ireland who are under 65 years is, depending on the prevalence estimate model used, somewhere between 2,906 and 4,311. Traditionally, the figures from the EuroCoDe model have been used to calculate prevalence, and those figures will be used throughout this study; this particular model estimates that there are approximately 55,266 people in Ireland with dementia, and of those, 4,311 have YOD (Pierse et al., 2019). It is nevertheless important to point out the differences between the various projections, as they highlight not only the difficulty in estimation, but specifically the importance of local and/or national prevalence studies to give accurate figures of the Irish situation.

Prevalence rates are measured by diagnosis, and when it comes to dementia in general, and YOD in particular, diagnosis is not a simple matter. As the availability of diagnostic services, or even the awareness that symptoms of dementia/YOD can be varying and different, many barriers to diagnosis and therefore care, still exist (World Health Organisation, 2012). This area is the focus of the next section.

2.4.2 Diagnosis

Diagnosing dementia is rarely straightforward, and diagnosis is often delayed: for YOD, the situation is worse again. An early diagnosis of dementia has been described as a gateway for

care, as access to services is restricted, future planning is made difficult, and no drug or non-drug treatments can be given without one (Knapp et al., 2007). Early diagnosis also means that a person with dementia may be able to become involved in his or her own care planning, as well as make any financial or legal arrangements (Illiffe et al., 2009) and it may also be cost-effective (Cahill et al., 2014).

Diagnosis is an important transition, as the person with dementia moves from uncertainty to a place where they can adapt to the new reality (Moore & Cahill, 2013). Birt and colleagues describe the period before diagnosis as ambiguous and unsettling, and that during this stage people are often 'structurally invisible' (Birt et al., 2017). From a human rights perspective, Cahill argues that diagnosis promotes dignity and autonomy, empowers the individual to take ownership of their illness, and to exercise choice and control over future options and decisions (Cahill, 2018).

Nevertheless, dementia is still consistently underdiagnosed, and where diagnosis does take place, it is often at a later stage of the disease (World Health Organisation, 2017). Some estimates suggest that generally YOD is not diagnosed until 2-4 years after the onset of symptoms (Kuruppu & Matthews, 2013; Mayrhofer et al., 2018; Novek et al., 2016; Van Vliet et al., 2013). Reasons for the delay are varied. Many General Practitioners (GPs) or health care professionals do not expect to see dementia in a younger person and so do not even consider dementia as a possibility; instead, issues are explained in psychosocial terms, and the person is erroneously diagnosed with for example burnout, depression or psychiatric disease (Chaston, 2011; Hoppe, 2019; Van Vliet et al., 2013). This can also be because FTD, much more common in YOD, has symptoms similar to depression or burnout and does not initially affect the memory (Van Vliet et al., 2013). Diagnosis may also be delayed due to the heterogeneity of symptoms, a number of symptoms that are not dementia-specific, and the higher prevalence of atypical dementias that characterise YOD (Mayrhofer et al., 2018).

There exists a great need to improve the diagnostic standards in relation to YOD, both in terms of health care professionals' diagnostic accuracy but also in terms of their knowledge and awareness (Chemali, 2012; Van Vliet et al., 2013). Younger people who have dementia are more likely to face barriers to both diagnosis and subsequent care, including accessing information about the illness, and access to support services and health care services (Novek et al., 2016). People with YOD and their carers tend to get a large number of referrals, and have described feeling like they are being passed from pillar to post before receiving the diagnosis (Van Vliet et al., 2011). Caregivers often feel that the medical profession is not

responsive or understanding of their concerns about dementia. Lack of responsiveness from GPs, and incorrect diagnosis leading to inadequate support or treatment also make up part of the delay in diagnosis (Van Vliet et al., 2011)

Carers and family members are often unaware that younger people could get dementia, and this - in combination with difficulties getting the person to contact medical help to investigate symptoms - also leads to a delay in diagnosis (Lockeridge & Simpson, 2013; Van Vliet et al., 2011). Denial is common in dementia, and can serve as a coping or protective mechanism, especially when, as with an illness like dementia, the concept of self is under threat (Van Vliet et al., 2011), which again may contribute to the delay in diagnosis.

Another issue in relation to diagnosis is that of appropriate disclosure of diagnosis. Disclosure of diagnosis is not a given, with rates varying considerably (Moore & Cahill, 2013). Reasons for non-disclosure given in studies relating to LOD are the lack of absolute diagnostic certainty from clinical information, the absence of effective treatments for progressive dementia, and the potential for adverse psychological responses to the diagnosis, and therapeutic nihilism (Cahill et al., 2006; Fisk et al., 2007). For example in one Irish study, 41% of the GPs surveyed reported that they never or rarely disclosed a dementia diagnosis to their patients (Cahill et al., 2006). In contrast, in a Swedish study, 39% of GPs reported they would always or often tell their patients their diagnosis of dementia: such disclosure patterns in dementia can be compared to a 95% disclosure rate in cases of terminal cancer (Ólafsdóttir et al., 2000). In an Irish needs-based study on persons with YOD, only just over half of the 61 participants had been told of their diagnosis (Haase, 2005).

Without a diagnosis, or without knowing what vaguely described 'memory issues' might be, accessing services is made even more difficult than it already is, for people with dementia in general but especially for persons with YOD (O'Shea, Cahill, Pierce, et al., 2017). With a diagnosis, the person with YOD will have clarity of what is causing their symptoms; nevertheless, diagnosis may lead to new uncertainties regarding how to deal with the illness, how it will affect them, and what its trajectory will be (Hoppe, 2019). The next section of this chapter will focus on the life course factors relevant for the person with YOD, starting with employment and moving on to children, caregiving, and finally, living well with YOD.

2.5. Life course influences of young onset dementia

This section looks at issues that affect the life course experiences of a person with YOD. The

particular stage in life that the person with YOD finds themselves in compared to those with LOD is evident in the two first topics, employment and children, and their atypical experiences continue to be analysed in the two remaining topics, caregiving and living well with dementia.

2.5.1 Employment

Many persons with YOD are in employment at the time of their diagnosis, and have a family to provide for and a mortgage to pay. Finishing work, or being let go because of the illness, is not only a major financial issue but is also part of a more fundamental change – work often makes up a big part of a person's identity and social network, and the loss of employment can therefore be keenly felt.

Work tends to be one of the first places where symptoms become visible as a person with YOD experiences them. Problems with work are reported by caregivers, for example that the person has become less productive, is unable to manage well-established tasks, or is going through conflicts at work (Van Vliet et al., 2011). The loss of employment and the provider role, and the financial difficulties that often follow, have both economic and social consequences. The identity of the person with dementia changes, and the sense of self-worth is affected; in addition, losing employment also means the loss of social contacts and meaningful occupation (Chaplin & Davidson, 2016).

Roach (2017) puts forward a compelling case why a person with young onset dementia can and should still be in employment. The nature of dementia means that employment can be problematic; performance issues together with personality changes can mean a distressing and difficult transition out of work, increasing the financial stress of the person with YOD and their family. However, Roach argues that just as it is possible to live well with dementia, it is also possible to work well with dementia, and to still remain an active and involved citizen who contributes to their community. She outlines how this can be done – chiefly by educating employees in how to work with a person with YOD, and to find out in what way the person can be best supported to continue contributing. This may mean a modification of activities, or increasing specific supports, or it may mean a new workplace completely – but the point is that the person with YOD can continue to work in a meaningful way, while maintaining personhood and biographical identity. Roach also stresses the importance of the work being purposeful for the person with YOD (Roach, 2017).

Roach's depiction of how employment for a person with YOD could look is unfortunately far from the general experiences of persons with YOD. Ritchie and colleagues (2015) found that it was not unusual for persons with early symptoms of YOD to be made redundant, or to be dismissed for poor performance. Increased stress and anxiety from work made the pressure on the person greater, affecting physical health and abilities. Participants described using a variety of strategies to manage or cover up symptoms, and to cope with the pressures (Ritchie et al., 2015). In Chaplin and Davidson's (2016) study, persons with YOD also described using strategies and tools to cope, such as diaries, calendars, and audio recorders. However, these tools were used secretly to hide the difficulties the person was experiencing from managers and colleagues; they may have been effective and successful coping strategies if they could have been used openly (Chaplin & Davidson, 2016).

Chaplin and Davidson's (2016) study chronicles the experiences in the workplace of five persons with YOD. Interestingly, the two that had higher ranked occupations, a businessperson and an engineer, reported being accommodated to a larger extent in being able to continue with their work, and maintained what they term a 'degree of control and choice' about their work. The remaining three participants, an HGV driver, a school assistant, and a nursing assistant, were all dismissed from employment with little consideration of how their remaining skills could be used; some were not even given an opportunity to say goodbye to their colleagues. Their lack of choice about remaining in employment compared to the participants in higher ranked occupations may have been as a result of their employer's view of them as lacking economic worth and being easily replaced – such behaviour and attitude placed additional burdens on these participants. The study overall suggested that persons with YOD who are employed in a lower status occupation are treated at best poorly, and at worst unlawfully when it comes to termination of their employment (Chaplin & Davidson, 2016).

Facilitating a person with YOD to stay in their employment, or even modifying the role to fit the person's current skills, would make a great difference to a person with YOD, both financially but also in relation to identity and to continuing life and planning for the future. A more stable financial and employment situation may also be beneficial in relation to family obligations, which tend to be more substantial for those with YOD, based on their stage of life. Such obligations, of course, involve children; many persons with YOD have young children under 18, or young adult children who are still dependent on their parents. The next sections deal with the experiences of children and YOD.

2.5.2 Children

It is believed that approximately one in four people with YOD have a child younger than 18 at the onset of dementia (Johannessen et al., 2016b). Most of the literature around children and dementia focuses on the experience of the child of a person with YOD. Growing up with a parent who has YOD is fundamentally different even from children growing up with a parent who has a serious illness such as cancer, or a chronic condition. Such disorders are often better understood and do not have the same unpredictability as YOD, and an illness like cancer may be easier to talk about for the child (Johannessen et al., 2016a).

Children growing up with a parent with YOD report great stress and emotional responsibility, and their experiences deviate drastically from the expectations of a 'regular' childhood (Johannessen et al., 2016a). Many report strains within the family prior to diagnosis of a parent, as the unexplained symptoms cause children to come into conflict with the parent with YOD. These conflicts are caused by irritation, misunderstandings, and frustrations, as well as a reaction to the tension between parents, or a loss of attention from parents – 28% of caregivers in one study reported that their children suffered from such difficulties pre-diagnosis (Van Vliet et al., 2011).

The stress of having a parent with a neurodegenerative illness, and the strain that comes with caring compound the experience for the children of people with YOD. Children may feel shame and embarrassment in front of their friends when their parent is forgetful or displays unusual behaviour, and as a result the child might withdraw from friends, or not confide in friends about their home situation (Johannessen et al., 2016a). Aslett and colleagues interviewed children who had experienced growing up with a parent with YOD and found that the participants had adapted their own lives as a result of their parents' YOD. While most of the participants in this study were not primary caregivers, they still experienced distress associated with caregiver stress, which often led to strong feelings of guilt (Aslett et al., 2019). Children also struggle to accept their parent's diagnosis, and experience loss as the parent with YOD can no longer care for them, or guide them or maintain a parental role (Carone et al., 2016; Chaston, 2011).

When a child takes on caregiving tasks for a parent, they risk trying to play a parental role before they are emotionally or developmentally able to manage adult responsibilities. Such a situation may affect the child's development and can lead to insecure attachment because of the lack of availability of both parents, and the responsibility of care (Millenaar et al., 2014). In addition to the caring role for the parent, a child may also come to play the role of parent for a younger sibling (Chaston, 2011). Millenaar and colleagues found that a third of children with

one parent with YOD suffered from mood disorders, and more than half of the children scored above average for burden levels (Millenaar et al., 2014)

One recurring issue in the literature was the concern that a child might feel worry and fear not only for their parent with dementia, but also for their healthy parent. The healthy parent is the person who cares for the parent with YOD, keeps the family's finances afloat (sometimes with great difficulty), cares for the other family members, and keeps the family together (Aslett et al., 2019; Chaston, 2011; Millenaar et al., 2014). The child tried to support the healthy parent as much as practically and emotionally possible, however all this combined to adding more to the levels of stress and distress for the child (Aslett et al., 2019).

Millenaar et al (2014) state that caring at a young age can increase the risk of social, behavioural and emotional difficulties, as well as problems with emotional and financial independence, and difficulties with peer relations and educational achievement (Millenaar et al., 2014). However, networks where children had a chance to meet others in the same situation are believed to help alleviate the situation (Mayrhofer et al., 2018). Studies have shown that children of persons with YOD feel overlooked and that their needs are neglected, and the opportunity to meet with others experiencing the same thing, and to get recognition and support, is very helpful. The caring aspect of having a parent with dementia is of course different from that of a spouse; the next section discussed caregiving issues and YOD.

2.5.3 Caregiving

Over 80% of the carers of a person with YOD are spouses/partners (Larochette et al., 2019). Spouses of persons with YOD have been shown to experience a significantly greater level of carer stress than spouses of older persons with dementia (Kaiser & Panegyres, 2006). They also report poorer emotional health and have less social support than carers for older persons with dementia: behavioural disturbances in YOD may also contribute to greater pressure for the carers (Aslett et al., 2019; Larochette et al., 2019). In addition, a study by Novek and colleagues (2016) comparing experiences of YOD and LOD in Canada show that participants with YOD reported a higher level of life stress.

Partners or spouses of those with YOD have to take on a three-fold role: caring for the person with dementia, caring for any children, and caring for their own wellbeing (Hoppe, 2019). Carers of persons with YOD tend to experience relational problems, family conflict, employment issues and accompanying financial difficulties, and their health-related quality of life on average is poorer than that of people caring for older persons with dementia

(Larochette et al., 2019). The spouse of the person with YOD may have to reduce their working hours to enable their caring role, or if they were not working, may have to find employment to support the family financially if the person with YOD can no longer work. Families may also struggle to find information, advice, and support in relation to pensions, benefits, insurance, and longer term arrangements. The person with YOD or the carer may already be caring for an older parent (Mayrhofer et al., 2018).

Behavioural problems are thought to be an especially significant issue for caregivers of those with YOD, as dementias such as FTD, which is much more common in those under 65 with dementia, are associated with higher levels of behavioural problems; these have an adverse effect on the psychological and physical health of the caregiver (Bakker et al., 2010). Kaiser and Panegyres (2006) found that 50% of spouses caring for a patient with AD reported mild depression or greater, compared with 75% for spouses caring for a patient with FTD (Kaiser & Panegyres, 2006). Younger people with dementia are cared for at home longer than their older peers, and younger carers report higher levels of psychological distress and greater difficulties coping with behaviours that challenge (Lockeridge & Simpson, 2013). In Lockeridge and Simpson's 2013 study on younger carers, female carers spoke of difficulties managing changes in their partner's behaviour related to aggression, sexuality, and sexual intimacy, finding these aspects particularly difficult to manage, and also feeling that there was no one with whom they could discuss such issues (Lockeridge & Simpson, 2013).

Like the person with YOD, caregivers also have many unmet needs in terms of service provision and support. For example, caregivers generally express interest in being able to meet others in a similar situation, to share experiences but also for purposes of social inclusion and connectedness – however lack of knowledge of other families was generally a barrier to creating such informal support (Mayrhofer et al., 2018). Caregivers also express a wish to talk to and receive support from persons who are not part of the family or the medical profession, and have a need to be heard and have their needs and opinions considered (Larochette et al., 2019). The very high stress of providing care that caregivers of persons with YOD experience can lead to burnout, and while this is often recognised by clinicians they cannot offer much in the way of community support or services (Chemali et al., 2012).

Caregivers of YOD have also been found to be reluctant to take on or implement help available, whether it is directed at the person with YOD or for themselves as carers. This can simply be explained by the fact that the help being offered is generally not suited for younger persons with dementia, and is not adapted to their professional and family situation

(Larochette et al., 2019). Caregiver stress, increased social isolation, financial worries, and vulnerability must be taken into account when services are created and offered (Kaiser & Panegyres, 2006).

While caregiving is undoubtedly stressful, finding positives in the situation can help, such as looking at the positive sides of the person with YOD, finding meaning in the caregiving role, and recognising the positives in life together, past and present (Pang & Lee, 2019). Finding purpose and wellbeing, and living well with YOD is important for caregiver and person with YOD alike, and is the final topic of this section.

2.5.4 Living well with young onset dementia

A diagnosis of dementia leads to changes in a person's perception of identity and selfhood: this is especially the case for persons with YOD, as they get diagnosed before what Harris and Keady call their 'older years' (Harris & Keady, 2009). 'Becoming' a person with dementia does not happen the moment diagnosis is given, but is rather a process that takes place over time, within a sequence of physical and social changes (Birt et al., 2017), and the adjustment to this process is a very individual experience. The person often experiences loss and grief in relation to the changing sense of identity and self, however it is not just the loss of personhood that is relevant but also how the self-perception and identity of the person is constructed at each stage of dementia (Tolhurst et al., 2014).

It is very important to capture the lived experience of YOD as closely as possible to allow for an understanding of the condition, however there is not much literature that considers personhood in relation to YOD (Tolhurst et al., 2014), nor is there much research relating to how a person with YOD experiences and evaluates their situation, and how to best support their coping resources (Thorsen et al., 2020). This is also the case in relation to research on living well with dementia; there are not many examples of where a person lives well with the illness.

Thorsen and colleagues (2020) carried out a qualitative longitudinal study in Norway on the quality of life of single persons with YOD. Presenting one case study from their research, the experiences of "Elsa", they approach the work with the perspective that the person with dementia is the 'true expert' of what is happening in their life. Thorsen and colleagues describe well-being and life satisfaction as having seven themes of significance: identity, connectedness, security, autonomy, meaning, growth, and joy. Over the three years of the study, Elsa experiences an erosion of self, a loss of the 'old' Elsa, and has issues with family

members, her son, and friends; she is struggling to cope with everyday tasks such as grocery shopping and having conversations with others, despite the help of a support person. However, as she moves to a nursing home later on in the study, her personality and spirits are revived. In the nursing home, she is able to carry out meaningful activities and interests, is training intensively to preserve her abilities, and uses a computer every day, as well as a camera. She is happy while being conscious of the fact that she is living in a nursing home, an obvious change for a previously very independent and outgoing woman. The experience of self and the ability to live well, the researchers conclude, can vary greatly in different living conditions (Thorsen et al., 2020).

A small English study looked at the impact on the well-being and cognition of people with YOD of structured gardening. The participants took part in therapeutic gardening over the course of one year, and reported a renewed sense of purpose and improved sense of well-being, even in the cases where their cognition declined over the year. This suggests that well-being can be maintained, even in the presence of cognitive decline in YOD, and also points to the importance of group belonging and meaningful occupation (Hewitt et al., 2013).

A Dutch-Nordic multicentre study (Millenaar et al., 2017) looked at the determinants of quality of life in person with YOD. One of their findings showed that disease awareness was positively related to quality of life. They concluded that awareness of one's illness is an important variable to realise limitations and make necessary adaptations, thereby being able to keep participating in important aspects of daily living. Awareness, they argue, is closely related to acceptance, and therefore has crucial implications for coping styles and strategies; coping with YOD and successfully adapting one's behaviour helps people feel healthier, and enables them to take part in their own care planning and future. This is a crucial point in relation to living well, and the authors emphasise the necessity of full disclosure of diagnosis; non-disclosure, or unclear euphemisms maintain the stigma associated with dementia, and also limit the empowerment of the person involved. The study also found that dementia severity was not related to a lower quality of life, a fact that is often assumed despite other studies showing similar results (Millenaar et al., 2017).

These few examples show aspects of living with YOD that are not often gleaned in the literature, or in the general discourse around dementia, whether YOD or LOD. While dementia is undoubtedly a difficult illness involving many hardships, the more constructive, helpful, or even positive sides of how a person can live well with dementia are often overlooked. Overly emphasising loss of ability and loss of personhood could, in Tolhurst's words, be argued to

“differ little from the biomedical perspectives that focus on degenerative aspects of neurological decline” (Tolhurst et al., 2014, p. 9). Currently, the label of dementia does not convey even the possibility of a sense of hope and continuity in everyday roles (Harris & Keady, 2009).

The vast changes that a dementia diagnosis brings mean that the person has to adapt to these changes and cope with physical, emotional and social challenges; this cements the importance of a shift in focus from symptoms and disability towards the capacity and potential of the person with dementia (Millenaar et al., 2017). In her book, Cahill (2018) described Mishra and Barrat’s reablement approach, which describes how the built and psychosocial environment can be adapted to compensate for an individual’s disability. Emphasis is not on deficits but on strengths and retained abilities: what the person can still do and what is important to them. The person is empowered to live well and participate in everyday life, and to gain or restore autonomy (Cahill, 2018).

Challenging the narrative which focuses exclusively on degeneration, loss, and the terminal nature of YOD would contribute to reducing stigma; such positive discourses could also help instigate appropriate supports and normalise services for persons with YOD and their families (Harris & Keady, 2009; Tolhurst et al., 2014). Rectifying the current narrative would take a major shift in social policy, public attitudes and health/social care funding, however one clear starting point is giving the individual voices of the persons with YOD a greater place in research, society, and in the care system to make their lives as good as possible (Harris & Keady, 2009; Thorsen et al., 2020).

It is of course important to acknowledge and not diminish the experiences of loss, sadness, grief, distress and frustration that a person with YOD may experience, but it is important to remember that they may also still experience humour, creativity, love, growth, participation, solidarity, and wellbeing (Cahill, 2018). It is not possible to create a world where it would be easy to have dementia, but there should be a world where it is possible to live better with it (Shakespeare et al., 2019).

2.6 Societal influences of young onset dementia

This final section deals with experiences related to societal or systemic influences. The issue of stigma is a major factor in living with dementia, whether YOD or LOD, however the experiences can be different for those with YOD. The availability of services and how to access

them is also a major issue in relation to YOD, as services specifically for those under 65 are generally extremely rare. These two topics are the focus of this section.

2.6.1 Stigma

Dementia is a highly stigmatised illness, and this remains true for persons with YOD. Low levels of understanding around dementia causes many misconceptions about the illness, and the perpetuation of stigma which results is present in the broader community, in providers of health care and social care services, and in people with dementia and their families (World Health Organisation, 2012). Part of the diagnostic delay with YOD is the fear attached to the possibility of dementia; both those with YOD and LOD and their families often minimise or disregard symptoms, fearful of the stigma attached to the disease (Hoppe, 2019). The stigma of mental illness is highly present in dementia, and the taboo and fear of cognition issues and of 'losing one's mind', as Chemali (2012) puts it, especially a young person's mind, contributes to the stigma (Chemali et al., 2012).

This can often be seen in the language used around dementia, where a person with dementia is routinely described as a "sufferer" and the illness as the most frightening one that exists (Cahill, 2018; Downs, 1997). In a 1997 article on personhood and dementia, Downs argues that terminology such as dementia *sufferers*, dementia *victims*, the *burden* of caring, or of family carers as *victims* will be replaced with more nuanced language as the focus on the individual person with dementia and their experiences and perspectives grows (Downs, 1997). Over twenty years later, however, such terminology is unfortunately still in use, with Cahill arguing that language depicting dementia in the media as a frightening, mysterious, relentless and fatal disease, focusing mainly on middle to end-of life stages, keeps reinforcing this stigma (Cahill, 2018).

The extreme fear surrounding dementia is therefore partly related to the way it is described - generally in hopeless, bleak and grim terms - and also to the fact that there is no cure (Hoppe, 2019). Therapeutic nihilism still prevails when it comes to dementia, even though psychosocial interventions can go a long way towards helping the person live well with the illness (Cahill et al., 2008). Studies have also attributed the stigma in dementia to the issue of a "spoiled identity", where the stigma comes from the belief that nothing can be done for the person with dementia (Lockeridge & Simpson, 2013).

One of the many negative consequences of the stigma attached to dementia is the isolation of persons with dementia, young and old, and how that affects them and their families.

Caregivers report friends and some family gradually drifting away and losing contact with both the person with YOD, and the caregiver – going so far as actively avoiding and distancing themselves. This causes pain and disappointment among persons with YOD and their carers and increases their social isolation. Such behaviour on the part of friends and family was ascribed to lack of knowledge, negative attitudes, and feelings of fear and embarrassment (Lockeridge & Simpson, 2013; Van Vliet et al., 2017; Werner et al., 2019).

Whilst an enormous problem for both YOD and LOD, the literature presents stigmatising experiences that are specific to YOD. For example, carers described instances when a member of the public believed the person with YOD was more capable than they actually were, because of the conflicting signals between their physically healthy appearance and their reduced cognitive and social skills; and carers describe developing coping strategies to cover for the behaviour of the person with YOD to avoid social embarrassment (Lockeridge & Simpson, 2013). Because dementia is generally associated with the ageing process, the ‘non-normative’ nature of YOD can also worsen anxieties around social judgements (Tolhurst et al., 2014).

In a study about caregivers of persons with YOD in Chinese culture, Pang and Lee (2019) explain that while dementia is seen as a loss of face (*mianzi*, or feeling shameful) culturally, this is especially the case when the person with the illness is young. The person with dementia does not only lose their social status, but they are also viewed by outsiders as bringing shame on their family. This led to the person with dementia isolating themselves further socially, believing themselves to be ‘useless’, while the caregivers were also reluctant to seek support and services because of the loss of face and the young age of the person (Pang & Lee, 2019).

It is not only the person with dementia, or their caregiver and family, who experience the stigma connected to dementia. Healthcare professionals experience different types of stigma because of their work with persons with YOD, such as disbelief that they can cope with such an ‘awful’ disease, the professionals themselves feeling great discomfort working with persons with YOD, or the professionals lacking knowledge of YOD and solely associating dementia with old age (Werner et al., 2019). Such stigmatisation is not only upsetting, but can also lead to diagnosis delay or misdiagnosis, or even suboptimal care or lack of service provision.

The challenge to put an end to the stigma of dementia is clearly a very large one. Increasing public and professional awareness of YOD would go a long way to reducing the experience of

stigma, as cultural norms and institutional practices all affect the wellbeing of stigmatised individuals (Lockeridge & Simpson, 2013; Werner et al., 2019). Werner and colleagues further argue that lack of knowledge has consistently been an important trigger of stigma, with partners of persons with YOD feeling isolated and concerned about the future, and professionals expressing frustration over lacking both the experience and the resources to help those with YOD (Werner et al., 2019).

Awareness, knowledge, and education are therefore some of the key points to any effort to combat the stigma surrounding YOD. By familiarising the general public with the possibilities to live well that still exist for a person with YOD, and by normalising their existence and experience, the illness would perhaps be slightly easier to deal with. Adequate supports, in the shape of services and interventions to help the person with YOD, could also be a positive in the sense that they would be empowered to live well and get the reinforcement they may require. The focus of the next part is on services for person with YOD.

2.6.2 Provision of services and supports

Services for younger persons with dementia tend to not be designed with the person with YOD in mind. Rather, services for LOD are generally assumed to be sufficient to address the needs of people with YOD. There is often an age-specific entry criterion to services, for example 65 years and over, and access to appropriate services is highly limited and its limited availability generally not standardised. The result is that persons with YOD tend to be excluded from services; they face an inverse ageism as there are few specialist services catering for them and their needs. This is compounded by the opinion held by many service providers that one approach to provision fits all (Chaston, 2011; Mayrhofer et al., 2018).

Services designed for older persons with dementia are not suitable for those who are younger for a number of reasons. Younger persons with dementia are more likely to be physically fit, healthier, are less likely to have co-existent major illnesses, be experiencing sensory changes, and are more likely to be sexually active. Their interests generally are not the same as older persons', their preferences tend to differ, and they identify more with staff than fellow service users (Bakker et al., 2010; Bjoernstad Tonga et al., 2016; Chaston, 2011). Moreover, being in the same setting as older people in advanced stages of dementia can be quite disturbing for those in early stages of the illness, who are trying to adjust to life with dementia while still being young, fit and active (Mayrhofer et al., 2018). The below summaries of studies outline some of the issues relating to services and persons with YOD; accessing services, how services

could be designed with the person with YOD in mind and as a contributor, and how a simple intervention may work.

Lockeridge and Simpson (2013) analysed the coping strategies adopted by younger carers of persons with YOD in England. Through qualitative interviews with the carers, the issue that came up consistently was the lack of suitable services. Carers recounted refusing to be 'bullied' into accepting unsuitable services, or how they had to battle every step of the way to get any form of support, and generally had to reach a crisis point before an intervention was offered. They felt that health and social care professionals lacked knowledge and understanding about YOD, and the specific needs of the person with YOD. Carers who had used support services for older persons had done so unwillingly, and felt that such services were unsuitable as they did not take age-related needs into account in relation to activities, stimulation and flexibility (Lockeridge & Simpson, 2013).

Bakker and colleagues (2010) analysed a single case study from the Netherlands, where the spouse of a man with YOD participated in qualitative interviews relating to what their needs were, how they changed over time, and what their experiences and views of health care services were. During the study period, the person with YOD moved from home to a dementia special care unit in a nursing home for older people which the spouse felt very strongly was not a good fit, as did her husband: "At first he was very rebellious; he did not want people helping him...he was among older people with dementia with fewer activities and he just waked around there, lost...he was in distress during that period, he said 'I'll jump off that roof'" (p. 638). After a few months, he was transferred to a special care unit for persons with YOD and his behavioural problems decreased and his well-being improved (Bakker et al., 2010).

In a study in England, Mayrhofer and colleagues (2018) investigated priorities for service planning and commissioning services for persons with YOD, with a view to informing a future study on community-based service delivery. They held roundtable meetings with persons with YOD and their carers, and also interviewed service providers. The study found that the persons with YOD made valuable contributions in the form of critical commentary on research findings, the current service provision, and on priorities for future work. The persons with YOD and their families suggested a framework where service models could be designed and evaluated, and where services would have the ability to create networks of support which would impact beyond the lifetime of an activity. The contributors saw social networks as being helpful in creating a post-diagnostic identity, where new social connections could develop, and also a

new sense of self for the person with YOD. They also highlighted that long-term support is important, as needs change over time as the illness progresses; what was needed the most was also that which was lacking the most, namely continuity of care. Mayrhofer and colleagues showed that involving the persons with YOD in assessing research in relation to what is important to them, and inviting them to suggest solutions or other proposals, is a successful way of co-designing services that address the challenges of accessing support for those with YOD. The community-based framework that the persons with YOD suggested may help address some of the bigger challenges of sustainability, continuity and cost of person-centred service provision for those with YOD. The study is also compelling in that it departs from 'needs based' research and instead involves persons and families affected by YOD in the development and co-design of community-based services (Mayrhofer et al., 2018).

Bjoernstad Tonga and colleagues (2016) carried out a study in Norway to see if manual-based structured cognitive behavioural/rehabilitation program could be beneficial for persons with YOD with depressive symptoms. They carried out 11 structured sessions with a woman with YOD, "Susan", which focused on cognitive-behavioural therapy, memory aids, reminiscence therapy, daily routines, and pleasant activities. For example, a list of pleasant activities was put together with things Susan liked to do. This list also included possible obstacles to these activities, and detailed planning relating to them. Susan was then able to pick out one activity from the list every evening, helping her to focus on it the next day. Another example was that of using a pocket calendar as a memory aid; in the diary, she could write down future events as well as previous activities. The latter proved to be especially useful, as she often forgot activities she had completed and therefore had negative thoughts, telling herself she was doing nothing while all her friends were working; seeing the meaningful activities that she had carried out in her diary helped. At the six month follow-up, Susan had a decrease in depressive symptoms and also reported feeling less depressed. She had, however, stopped using her diary as she kept forgetting to write in it, which highlighted the need for "booster-sessions" where the person can go through the interventions at appropriate intervals. While only being one single case study, the study still indicates that the challenges of living with YOD may be helped through appropriate and relevant interventions (Bjoernstad Tonga et al., 2016).

These examples are from England, Norway and the Netherlands, countries with a high standard of living and universal healthcare. In general, tailored services for those with YOD are rare; and organising them is demanding because while they constitute a group with great needs, persons with YOD are not a large group (Johannessen et al., 2016b). This means that they are often on their own in finding and accessing services, with many carers feeling that the

responsibility to find suitable services and available help is left to them alone (Chaston, 2011). Services adapted to persons with YOD with a focus on meaningful and pleasurable activities have been shown to be of benefit for the person with YOD and their families (Bjoernstad Tonga et al., 2016), and there is no reason why these should not be available to this particular group. The perpetual problem of lack of resources and absence of policy targeting the rights and needs of persons with YOD must be dealt with in order for this group to have access to appropriate services (Chemali et al., 2012).

2.7 Irish context

While the above sections explored literature relating to YOD mostly in contexts other than Ireland, the next section focuses specifically on dementia from an Irish perspective. The first part details the development of general dementia policy in Ireland, while the second part looks at the Irish experience of YOD.

2.7.1 Development of dementia policy in Ireland

One of the first forays into dementia policy was the 1999 report *An Action Plan for Dementia*, commissioned by the National Council for Ageing and Older People. Its authors, Eamon O'Shea and Siobhán O'Reilly, produced a detailed plan intended to serve as a guide for policy makers and a model of best practice. They advocated person-centred care and highlighted the fact that community support services were under-developed and fragmentary, and that persons with dementia generally did not come into contact with health and social care services until a crisis occurred. This had led to a system of in-patient care for people with dementia, rather than the more appropriate anticipatory and continuous community care in partnership with the person with dementia and their family (O'Shea & O'Reilly, 1999). The report fearlessly proclaimed that "Action on the treatment of dementia can be delayed no longer" (p. 5), and ended with the simple statement, "The time for action is now" (O'Shea & O'Reilly, 1999, p. 141). However, the wait has continued as despite promises, implementation was inadequate (O'Shea, 2007).

The Action Plan for Dementia was followed in 2007 by *Implementing Policy for Dementia Care in Ireland - The Time for Action is Now*, which reiterated the need to make dementia a national health priority and to implement the recommendation of the 1999 *Action Plan on Dementia* regarding primary and community care solutions and support structures (O'Shea, 2007). This

situation persisted until 2011, when a commitment was given by the incoming government to formulate a National Dementia Strategy, but due to the dire economic situation the country was in at the time, the new strategy did not have any additional resources towards its development or implementation. As part of their overall investment in dementia in Ireland, the philanthropic group Atlantic Philanthropies included direct financial support for the new strategy (Hennelly & O'Shea, 2017).

The investment by the Atlantic Philanthropies in Ireland between 2011 and 2016 strengthened the partnerships between stakeholders in dementia care in Ireland, and accelerated action in areas of advocacy and policy, which ultimately helped in the development of the National Strategy (O'Shea, Cahill, Pierce, et al., 2017). Atlantic Philanthropies were also the funders of the *Creating Excellence in Dementia Care* report, which provided an evidence base for the creation of a National Dementia Strategy (Cahill et al., 2012). However, it is worth noting that such once-off funding for research and services can be discontinued when the funding period is over, and the services might not become embedded into the service delivery system; this is to the detriment of the persons using and relying on the service (Fox et al., 2020).

In 2014, the long-awaited and much anticipated Irish National Dementia Strategy was published by the Department of Health. It came into being after a comprehensive consultation process which included the abovementioned *Creating Excellence in Dementia Care* report, as well as submissions from stakeholders, reviews of the Irish policy context and international dementia plans, clinician roundtable discussions, input from an advisory group, and workshops for people with dementia and their carers (Hennelly & O'Shea, 2017). The Strategy outlined six Priority Action Areas, namely better awareness and understanding of dementia; timely diagnosis and intervention; integrated services; supports and care for people with dementia and their carers; training and education; research and information systems; and leadership (Department of Health, 2014). It is based on two main principles, personhood and citizenship; the inclusion of two such concepts represent what O'Shea and colleagues called "a major breakthrough in the effort to develop a counter-policy frame to the traditional biomedical model that has dominated the dementia landscape in Ireland" (O'Shea et al., 2017, p. 21).

A number of criticisms have been raised against the Strategy. For example, none of the priority actions are accompanied by any reference to how to implement person-centred care or a person-centred system, or how to ensure autonomy for the person with dementia (Hennelly & O'Shea, 2017). Moreover, the strategy does not make any commitments to guaranteeing the human rights of persons with dementia (Cahill, 2018). It also lacks any explicit consideration of

outcomes, and the priority actions do not have any timelines indicating when the action will be realised, nor do they specify how each action is to be financed. In addition, the strategy lacks sufficient focus on prevention and healthy lifestyle choices; the absence of choice in service provision, which is heavily dominated by residential care; and entitlements to post-diagnostic information and social care support to help families providing care at home (O'Shea et al., 2017).

Another deficiency in the strategy relates to home-based care. While the Strategy secured investment for the Home Care Package Scheme, there are still major differences across the country in relation to home care delivery, with great variation in the type and amount of services available (O'Shea et al., 2017). But the fundamental weakness around home care services in Ireland is that, compared to most European countries, there is no statutory scheme entitling a person to social care services. There is, however, a statutory right to apply for financial assistance with the cost of long-term residential care, meaning that persons with dementia may be admitted to long term institutional care even when it is not appropriate, due to the low level or absence of home-based care (Cahill, 2018).

Nevertheless, despite all this, the Strategy provides – in principle – for the improvement and expansion of dementia care, more integrated care, and more public awareness of dementia, and, crucially it integrates dementia into future government policy (O'Shea, Cahill, Pierce, et al., 2017). The creation of the Irish National Dementia Strategy was ground-breaking after many years of not recognising or engaging with the issue of dementia. Almost immediately after the Strategy's publication, the National Dementia Office was created to oversee the implementation of the Dementia Strategy, and action on raising public and professional awareness and understanding of dementia, workforce training and education, intensive home care packages and timely diagnosis and intervention began quickly (O'Shea, Cahill, Pierce, et al., 2017).

The National Dementia Strategy has been part of the major shift in the discourse around dementia which has taken place in Ireland over the last ten years, and the genuine attempts to change the system of care for persons with dementia (O'Shea et al., 2017). It is, however, important to recognise and be cognisant of the fact that while the Strategy was a very important step forward, development and implementation are equally, if not more, important. Fifteen years elapsed between the publication of the 1999 *Action Plan for Dementia*, which called for immediate action on dementia, and the publication of the Irish Dementia Strategy –

to ensure that persons with dementia do not have to wait another 15 years for words to become tangible improvements, implementation is fundamental.

In the *Mid-Term Review of the implementation of the National Dementia Strategy* (2018), the Department of Health and the National Dementia Office stress advances made since the creation of the Strategy, but also state that full implementation of the Strategy will require further investment in the health care and social care system. Further, they acknowledge that “...health service resources are finite and it will be difficult to obtain resources on the scale that is needed” (p. 9). They also cite the lack of reliable national data on dementia services in Ireland as an impediment, as much of the work up to date has been devoted to collecting baseline information on dementia service structures (Department of Health & National Dementia Office, 2018). Even taking these explanations into account, it is still imperative that persons with dementia in Ireland and their family members get the improvements in services that they have waited so very long for, especially as they are now prescribed in the Strategy; Government grievances about funding should take into account how ineffective and costly not providing such services ultimately is.

The cost of dementia in Ireland is estimated to be nearly €1.7 billion every year, with 48% attributable to informal care provided by family and friends in the community; 43% to long-term residential care; and formal health and social care services 9% (Pierse & O’Shea, 2017). These figures show the extent to which family carers are providing care, as well as the low level of primary care and community-based care at the expense of the family carer (Connolly et al., 2014; Pierse & O’Shea, 2017). In recent years, many countries have moved towards trying to support people with dementia at home, rather than focusing on residential care, as staying at home is generally the preferred option, and also tends to be more cost-effective (Carter et al., 2019). Moreover, investments in personalised community-based supports for persons with dementia who are on the boundary between community and residential care have been shown to provide economic benefits, and have the added benefit of taking pressure off family carers (O’Shea & Monaghan, 2017). Enabling persons with dementia to stay at home longer, instead of being admitted to residential long-term care reduces cost of care: however as mentioned, the poor provision of community-based care and lack of statutory rights in Ireland means that residential care is often the main option. One of the main issues with Irish government policy has been the imbalance in spending on care, with the government is spending more than twice as much on residential care as on community-based care, €962 million relative to €408 million annually (Carter et al., 2019).

2.7.2 Young onset dementia in the Irish context

When it comes to YOD, the policy and research context in Ireland is varied. While the majority of the influential policy documents, as well as the National Strategy, tend to mention persons with YOD and their specific needs, there is little strategy and limited action addressing these needs.

An Action Plan for Dementia dedicated a section in the Special Needs Groups chapter to YOD, highlighting the specific needs and challenges they face. It also discussed the difficulties persons with YOD face when trying to access existing service provision, with those with YOD consulted for the Action Plan faring worst of all in relation to appropriate provision of community-based and residential services. The authors conclude that due to the poor provisions, those with YOD are likely to fall through these cracks in the system and end up in inappropriate care settings, and specifically recommend: “particular attentions should be paid to the needs of people with early onset dementia with appropriate care packages drawn up to reflect the special circumstances of people in this group and their carers” (O’Shea & O’Reilly, 1999, p. 113).

The 2007 report *Implementing Policy for Dementia Care in Ireland - The Time for Action is Now* reiterated these points and the need for development of new services specifically for persons with YOD (O’Shea, 2007). *Creating Excellence in Dementia Care* included a section on prevalence and incidence of cases of YOD, and emphasised the need for reliable epidemiological data for this group. It also mentioned YOD and its specific needs and regular disadvantage throughout the report in relation to the diagnostic process, home care services, day care services, residential care, and so on (Cahill et al., 2012). The National Dementia Strategy mentions YOD in relation to the often difficult diagnostic process, and the specific needs persons with YOD may have because of their stage in life where they may have children and financial obligations, and stress the importance of the Strategy addressing the needs of all people with dementia, including those with YOD. It also mentions the needs of persons with YOD in relation to primary care, mental health care, and care in the community, stressing that equity must apply to service provision (Department of Health, 2014). However, these are brief mentions of a few sentences and no immediate improvements or solutions are offered for persons with YOD, for whom there are no dedicated services (O’Shea, Cahill, Pierce, et al., 2017).

The main body of work relating to young onset dementia in an Irish context is the Alzheimer Society of Ireland (ASI)-funded 2005 report by Trutz Haase, *Early-Onset Dementia The Needs of Younger People in Ireland*. It carried out a needs analysis of younger people with dementia,

examining among other things what care services were needed. The study initially intended to interview persons with YOD, but this proved too difficult and primary caregivers were interviewed instead. The main findings that emerged were around the following issues: the need for a timely diagnosis; informing the person with dementia about their condition; supporting flexible care arrangements; improving home help, day care, respite care, residential care, medical care and financial support; and providing counselling (Haase, 2005). The first of its kind, the Haase study of persons in Ireland with YOD was both important and timely, as Irish data specifically about YOD until then was inadequate and disjointed. While the study is 15 years old, and the participants were all family members rather than individuals with YOD, it paints a bleak picture of the situation for those with YOD and their families.

In September 2020, the National Dementia Office published a report entitled *Young Onset Dementia: A Review of Diagnostic and Post-Diagnostic Processes and Pathways*. Authored by Fox and colleagues, the comprehensive report investigates the diagnostic and post-diagnostic support needs of persons with YOD in Ireland, through interviewing persons with YOD, their spouses and children, and healthcare professionals and managers working in dementia services. They found that people with YOD are significantly disadvantaged in the Irish health and social care system, and participants living with YOD reported delays prior to diagnosis, inappropriate disclosure of diagnosis, the emotional effect of diagnosis, and a lack of services (Fox et al., 2020). The findings highlight the shortcomings in caring for those with YOD in Ireland, and the report makes a number of detailed recommendations in relation to developing Irish diagnostic and post-diagnostic care.

Fox and colleagues begin by highlighting the unique needs and experiences that each individual person with dementia will have, and emphasising the importance that the individual remains central. In relation to diagnosis, the report recommends that diagnostic processes should be streamlined, and that any disclosure of diagnosis should be made with consideration and be planned in advance, and that information about YOD and related issues should be provided in a phased way, to ensure that the person and their family are able to take it all in. Further, they recommend that diagnostic and post-diagnostic services should be integrated and the pathway between the two should be clear; each person with YOD should have a named point of contact post-diagnosis, such as a dementia care co-ordinator. In addition, post-diagnostic outcome-focused interventions and approaches should be provided to support the person with YOD to maintain their standard of living; legal and financial advice and information should be available; dedicated information and support services for the families of persons with YOD, including children, should be available. The authors also

recommend that information on advanced care planning and palliative care be made available as and when is appropriate; and finally, that a whole-of-community approach is adopted to increase awareness amongst the public of YOD, and to combat stigma (Fox et al., 2020).

The large scope and extensive nature of the report means that Fox and colleagues have made an extremely important contribution to this generally overlooked population in Ireland. Their focus specifically on YOD, and their investigative depth in relation to diagnostic and post-diagnostic support needs adds to the evidence base in relation to the Irish context, and should serve as an important tool for policy makers. They have contributed data to an area which has been very under-served, and shine an important and timely light on the individual person with YOD and their lived experiences.

2.8 Summary

This chapter began by describing the creation of the literature review, and then provided a helpful insight into the development of the models and conceptualisation of understanding dementia. It gave a summary of the definition and prevalence of YOD, and how it is different from LOD. Healthcare-related issues such as diagnosis and disclosure were also discussed. The chapter further looked at areas of specific interest to YOD in relation to the life course, such as children, employment, stigma, services, and caregiving. Living well with YOD was an area of particular interest where the existing literature provided great insight, however there were not many studies in the area. Likewise, while there were more studies around children and YOD, most were from the point of view of the child of the person with YOD, as opposed to the experiences of the person with YOD in relation to their children.

These two gaps were of particular interest, as the findings of this study covers both of these topics from the perspective of the person with YOD. The importance of hearing the voice of the person with YOD is crucial, and their contributions are essential. This study was built around the idea of including the person with YOD in the research; they were the primary target for recruitment, as it was their subjective experience that was sought. The next chapter, *Chapter Three: Methodology and methods*, further explains the methodological approach taken in creating the study, as well as the practical methods of data collection and related issues.

CHAPTER THREE – METHODOLOGY AND METHODS

3.1 Introduction

The aim of this PhD study was to explore the experiences of persons with YOD in Ireland in relation to health care, social care, and their lived experience. A suitable approach had to be adopted that tried in as much as possible to address all ethical considerations and predict potential pitfalls and issues, while still keeping the voice and the autonomy of the participant at the core. While qualitative methods are generally the best way of eliciting in-depth and personal information, there are many different approaches within qualitative research which all have their own merits; for this study, IPA was considered the most suitable approach. This chapter will elaborate on the research strategy chosen, the ethical challenges and considerations, and the more practical aspects of research methods, data collection, and analysis.

3.2 Research design

3.2.1 Qualitative research strategy: Constructivism and phenomenology

In order to explore the lived experiences of persons with YOD in Ireland, an approach was needed that allowed full insight into relevant issues, and which gave participants every opportunity to speak freely and openly.

Blaikie (2007) describes approaches to social enquiry as being concerned with two things: the logic used to develop research and new knowledge and the steps and procedures this involves, and the philosophical and theoretical underpinnings and assumptions about what constitutes social reality and how research can produce knowledge. In approaching the study and in order to properly delve into the issues being studied in this PhD, I decided at a very early stage that the most suitable course of action was to use a qualitative approach. This allows for a more in-depth analysis of the issues at hand, and gives more insight into what each individual is experiencing and enables participants to express themselves fully.

There are many ontological and epistemological approaches to research: in this case, the main issue of the study lent itself to approaching a constructivist base for the research. Crotty (1998) states that in constructionist thought, meaning is constructed by human beings as they engage with the world which they are interpreting, regardless of any assumed meanings.

Nothing can be described in isolation from the conscious being experiencing it, and likewise no experience can be adequately described in isolation from the individual who is experiencing it. As one of the key words in the research question is experience, the constructivist approach to what this can mean resonated with the core of this study.

Rephrasing Crotty's statement above, for this study, the conscious being describing their experience is the person with YOD; and their experience is their lives with YOD. The experience is intertwined with the dementia, and experiences will be coloured and interpreted by each individual. This, Crotty argues, is the point which is central to constructivist theory: there is no 'true' or objective interpretation of an experience or an issue, but rather an interpretation where each individual engages with their world and makes sense of it through a historical, social and individual perspective (Crotty, 1998).

Expanding this point, Creswell highlights the importance of researchers who theorise in the constructivist vein to focus on the "specific context in which people live and work in order to understand the historical and cultural settings of the participants" (Creswell, 2007, p.21). This is crucial to this particular study, in which not only each individual's specific context may vary, but their experiences also. Crotty goes on to state that constructionist research invites the researcher to be open towards an object and see the potential for a new or richer meaning – it is an invitation to reinterpretation. This captures the essence of this study, in that I as the researcher maintain maximum openness and flexibility to ensure the participants are able to express themselves fully, and I am then able to (re)interpret each participant's experience.

Building on the central role of experience in constructionism, the area of phenomenology was the next stop in the search for the most suitable way of studying the individual experience. Smith and colleagues (2009) describe phenomenology as a philosophical approach to the study of experience, focusing on what the experience of being human is, and how we can come to understand experiences of the world. Phenomenology is also concerned with how social life is constructed by those who participate in it, making them agents interpreting their own experiences (Denscombe, 2007). One of the first to conceptualise phenomenology was Edmund Husserl, who argued that in order to examine an everyday experience, one must step outside of this everyday experience; through adopting a phenomenological attitude, a person turns their gaze away from an object, and turns their gaze inwards, to the perception of that object (Smith et al., 2009). It is through this process of consciousness that a person gains objective knowledge, as it is through the medium of consciousness that we encounter the world (Larkin et al., 2006). The study of human experience, thus, is aimed at discovering

underlying, fundamental aspects of experience that lie at the very heart of the human experience (Denscombe, 2007).

One of Husserl's students, Martin Heidegger, continued to develop the idea of phenomenology with an additional existential emphasis; using the term *Dasein* (being, or presence) for the uniqueness of a human being, his primary concern was around the ontological issue of existence itself, and how *Dasein* enters into a pre-existing world of culture and language and objects, from which it cannot be detached in a meaningful way (Smith et al., 2009). *Dasein* implies that the very nature of human beings is to 'be there'; in other words, a person is always located within and involved in some type of context, and it is in the context of our various involvements with that world that we are understood (Larkin et al., 2006).

Focusing also on the hermeneutic side of phenomenology, Heidegger cemented phenomenology's aim of investigating the essence of human experience (Denscombe, 2007). Hermeneutics is the theory of interpretation, and in Heidegger's conception, hermeneutics implies that in relation to *Dasein*, the lived engagement is always through interpretation: a phenomenon appears, but it is the phenomenologist making sense of that appearance. This also includes the concept of fore-conception, where Heidegger emphasised the fact that a reader always brings prior experiences or preconceptions – fore-conception – into an encounter with an object. Priority should be given to the new object, and not to the fore-conceptions, however it is essential to bracket these fore-conceptions through being aware of them (Smith et al., 2009). This also alludes to the hermeneutic circle, which describes the symbiotic relationship between the part and the whole: to understand any given part, you look at the whole, and to understand the whole, you look at the parts, which in turn describes a non-linear style of interpretation (Smith et al., 2009).

3.2.2 Interpretative phenomenological analysis

At the heart of this PhD was the wish to explore the issues facing a person with YOD, in relation to health care, social provisions and their lived experience. To this end, it was obviously important to truly understand the participants' individual experiences, in order to develop a deeper understanding of the issue. The phenomenological philosophy, and its specific focus on the individual experience of a phenomenon, therefore, was in my opinion the most suitable way to get to the core of these experiences. I had also considered adopting a constructivist grounded theory approach, due to its focus on human interaction and its systematic way of analysing data, however in light of my wish to focus on the phenomenon at

hand (that of YOD), individual experiences, and the lived reality of the participants, a phenomenological approach was more appropriate.

Combining all of the above, I came to the decision that the best methodological approach for this study was IPA. This particular approach allows for in-depth analysis as the experience of the 'phenomenon' – having YOD – emphasises the first-hand experience of those living it. Smith and colleagues (2009) describe the complex understanding of 'experience', which is a lived process unique to the person's embodied and situated relationship with the world: in IPA, the researcher's attempt to understand an individual's relationship to the world is necessarily interpretative, and focuses on her/his attempts to make meaning of her/his experiences. Using hermeneutic theory, the theory of interpretation, Smith and colleagues (2009) describe the relationship between the part and the whole – to understand any part, you look to the whole, and to understand the whole, you look at the parts. They also stress the influence of ideography, being concerned with the particular. IPA, they explain, is concerned with the particular in terms of detail and therefore depth of analysis, but also in terms of how particular experiential phenomena are understood from the perspective of particular individuals in a particular context (Smith et al., 2009).

This resonated with my study on many levels. The experiences of persons with YOD needed to be examined in terms of a societal and historical perspective – the part and the whole – but the importance of the particular enabled me to analyse in-depth experiences within a specific context. IPA is concerned not only with individual experiences but also stresses the importance of the researcher in analysing these. Larkin and colleagues (2006) emphasise that while an IPA researcher aims to describe and analyse an experience on its own terms, without any preconceived assumptions on the part of the researcher, this is nearly impossible. They state that while researchers can never fully escape preconceptions, as we are all situated in our own contexts of how we observe the world, researchers should still attempt to be as free of preconceptions as possible.

Smith highlights the essential role of the researcher in making sense of a participant's experiences: "the participant is trying to make sense of their personal and social world; the researcher is trying to make sense of the participant trying to make sense of their personal and social world" (Smith, 2004, p. 40). Further, Smith and colleagues (2009) state that while analysing a participant's experiences requires closer interpretative engagement from the researcher, it is very important to be aware of one's own preconceptions. The researcher may not even be aware of certain preconceptions prior to analytically approaching a research topic

or empirical investigation of it, necessitating reflective practices throughout the research process.

Thus, in the words of Smith and colleagues, by choosing IPA as a method for research, “we commit ourselves to exploring, describing, interpreting and situating the means by which our participants make sense of their experiences” (2009, p. 40). This is precisely the approach that I wanted to use in order to make sense of the experiences of people with YOD in accessing health care and social care services.

3.3 Ethical considerations

3.3.1 Including a person with dementia in research

The subjective opinions and experiences of the person with dementia are the cornerstone of this study, and were the main focus from the outset. In order to achieve this, I was determined to interview the person with dementia when collecting data, as opposed to interviewing a proxy for the person, or a partner or spouse. Including a person with dementia in a study on the experiences of people with dementia may seem like a natural and logical course of action: however, this has not been and is not always the case. Research into dementia has tended to be grounded in the biomedical model portraying those with dementia as diseased brains rather than individual people, with the result that their voice has often not been included in research (Wilkinson, 2002). However, this has been changing in more recent times, and hearing the voice of the person with dementia is now regarded as important in terms of promoting their social inclusion, and improving services (Pesonen et al., 2011).

As people with dementia have been excluded from research, proxy accounts by carers or family members have tended to be the chief insight into the person’s experience (Hellström et al., 2007). Relying on proxy accounts, however, cannot be a substitute for listening to the person who has the illness – the view that persons with dementia cannot express themselves is being constantly challenged (Hellström et al., 2007). While some of the participants in this study had family members present in their interviews, this was the person’s choice; this will be discussed further on in section 3.5.1 (In-depth interviews).

Assuming that people with dementia cannot participate in research or are unable to share their views and experiences with researchers and others reinforces negative stereotypes of incapacity (Wilkinson, 2002). Hellström and colleagues (2007) argue that excluding people with dementia from research that is being carried out about them is an affront to their

identity: if they were included, it would enhance their dignity and personal identity. Persons who can be deemed superficially to have no ability to hold or express opinion may still be able to give information about their views and engage with the world (Sherrat et al., 2007). Moreover, while the ability to articulate may be compromised in people with dementia, evidence suggests they can communicate their experiences and quality of life even in the middle to late stages of dementia (Slaughter et al., 2007).

In the past, persons with dementia have also been excluded from research on the assumption that research may cause potential emotional distress, and that the exclusion is there to protect them (Hellström et al., 2007). This paternalistic approach is rejected by Sherratt and colleagues who argue that “reduced capacity is not a sufficient justification to exclude people from taking part in research and may in fact be denying them the right to be party to an issue that is of fundamental importance to them” (2007, p. 471). They argue that people who are deemed to lack capacity, for example a person with dementia, should not be denied their right to help other people, such as the right to contribute to research.

However, there is also the argument that persons with dementia can be considered a vulnerable population, as apart from the cognitive aspect, their illness may affect areas of the person’s life such as identity, autonomy and independence (Pesonen et al., 2011). This potential vulnerability is important to acknowledge in relation to taking all ethical issues into consideration; however, it is crucial to not let such concerns spill over into the type of paternalistic stance so emphatically rejected by Sherratt et al. (2007). Rather, the assumption should be that the person with dementia can and should be included in research, and not the other way around, again echoing the disability activist saying, “*nothing about us without us*”.

I agree wholeheartedly with this stance, and the decision to interview persons with dementia, and to not include a carer (where possible), was taken on this basis. The focus should be on the *person* with dementia and their experience of dementia, as opposed to solely being a person with *dementia* where the illness takes precedent over the individual. It is earnestly hoped that this was achieved in this study.

3.3.2 Informed consent

Despite my firm belief that a person with dementia has every right and ability to participate in research, there were a number of ethical issues to consider. One main concern was to ascertain that the person with dementia could freely consent to participating in the research. Careful monitoring of consent is necessary to ensure that participation in the research is

voluntary and that the person fully understands what the research will entail. Given the nature of dementia and its effect on memory and other cognitive functions, this may at times prove a challenge. To address this, I adopted the Dewing approach to acquiring consent in dementia research (Dewing, 2002). All participants were provided with full and comprehensive information about the study prior to being asked to consent to participate. They were given information sheets detailing the purpose of the research and providing full explanation as to what participation will entail. Where interest was expressed and the researcher contacted, the potential participant was told about the main objectives of the research, the topics to be discussed and what the questions would cover, and were given the opportunity to ask any questions or voice any concerns.

Accordingly every reasonable effort was made to ensure that the potential participant had a good understanding of the research study and what they were agreeing to become involved in. Thus, through a person-centred approach which valued the person with dementia and that was situation-specific, it was possible to determine the person's capacity to give informed consent in a way that safeguarded the person's rights and maintained their autonomy (Pesonen et al., 2011). Also, it was crucial that seeking consent and ensuring that the person with dementia was willing to participate was a process that continued throughout the interview; it was also important to emphasise that the participant could choose to withdraw from the interview, or the larger research process, at any time or at any stage of the research.

3.3.3 Interviewing a person with dementia

Due to the nature of dementia the interview process may be affected by problems such as language, confusion and disorientation. In such situations, strategies such as active listening, rephrasing questions, tolerating silence and giving the person with dementia time were necessary (Pesonen et al., 2011). By being sensitive to the ways in which dementia might affect the ability to communicate, a researcher can facilitate the person's inclusion in the research and respect their dignity in the process, by simple actions such as allowing long silences, or not trying to jump in and 'help' a person who is struggling to find a word, or not try to guess what the person wants to say before they have said it. This means that the researcher needs to be skilled in both verbal and non-verbal communication, as well as being knowledgeable of and sensitive to the ways in which the person communicates (McKeown et al., 2010). Eliciting information from a person with dementia in an interview also demands that the researcher is open to interpreting what a person with communication difficulties is trying to say in their own way.

One such example in this study came from one of the participants with the lowest level of insight and communication skills, Seamus. While Seamus was able to understand the purpose of the study and consented to participation, he had a difficult time expressing himself. Where he did not find the specific word, he was still able to communicate to the researcher what he wanted to say:

Interviewer: ... and you are not working anymore

Seamus: no, no

I: so did you have a, like an early retirement or did you just stop working or

S: emm, well when that happened, it was kind of tough, emm, yes, I did an awful lot of this stuff [shakes hands]

Seamus had had two brain seizures, which is what he was alluding to with the shaking gestures – meaning that he was not able to continue working after his seizures. So while interviewing Seamus demanded that I employ all of the examples of interviewing techniques listed above due to his communication difficulties and lower level of insight, he was still able to convey important points such as the experience of giving up work ('...it was kind of tough...'). Section 3.5.3 (Levels of insight and ability of participants) discusses the varying levels of insight and ability of the participants further.

In addition to interviewing and listening skills, the researcher must also be prepared that the interviewee with dementia may become emotional, as strong emotions may surface during an interview. In this sense, it is no different from any other research interviews with participants who are not cognitively impaired, as discussing a personal, difficult and fraught topic makes emotional reactions more likely. Should this occur, Slaughter and colleagues (2007) suggest that the researcher simply pause the interview, do what is possible to be supportive, and discontinue the interview if that is the interviewee's expressed choice. It is also useful for the researcher to provide the participant access to suitable professional support if they were to become upset. This could involve for example providing a list of numbers the person could contact for dementia-specific support groups.

3.3.4 Using the word dementia

Dementia is a very stigmatised illness, to the extent that even the word dementia is sometimes shunned in favour of other, more descriptive and less direct terms. McKeown and colleagues (2010) summarised a number of studies where researchers had chosen to either

use the euphemism 'memory problem' rather than the term dementia unless the participants used it themselves, or had decided on not using the word so as to meet the participants on their own terms by not insisting they use the word dementia.

As a prerequisite for participation in this study was a diagnosis of dementia, I did not expect it would be a major issue. However, I still had to give thought to how I phrased basic communications such as the Participant Information Sheet, or parts of the questions in the interview schedule, in order to avoid inadvertently creating upset or unease. McKeown and colleagues (2010) state that since the values of openness and transparency form a large part of active involvement in research, this should be extended also to honesty about diagnosis.

While I had no wish to insist that a participant use the term dementia if they were uncomfortable with it, the very fact that I needed to consider the extent to which I use the term 'dementia' highlighted the stigmatising nature of the illness, and the fear of labelling that exists. For example, Cahill and colleagues (2012) observe that persons with dementia may avoid accessing support from the Alzheimer Society due to the fear of being labelled. Similarly, Moore and Cahill (2013) found in a study on General Practitioners in Ireland and Sweden that in both countries the General Practitioners tended to go out of their way to not say the word dementia when giving their patients a dementia diagnosis.

I decided to use the word 'dementia' rather than synonyms about memory loss in my communications with the participants in order to de-stigmatise the word, and to be frank about the condition. However, if a participant was uncomfortable this would be taken into account and the word avoided so as to not cause undue stress – it was important that as a researcher I was aware of the fear of labelling that exists, and that I exercised discretion when necessary.

3.3.5 Researcher reflexivity

The process of qualitative research is a process of interpretation, as the researcher interprets the data and conducts the analysis based on their own understanding – this, in turn, is a creation of the researcher's self (Denscombe, 2007). The researcher's beliefs, feelings, biases, and overall character become part of the research, as these all play a part in influencing the researcher's thoughts and awareness, whether consciously or not. Even if employing all the practical methodological advice and rules regarding analysis, a researcher reading a transcript is still always influenced by their own biographical presence (Smith, 2004). Indeed, a

researcher can never fully avoid or escape the preconceptions that their own world brings; however that does not mean that one should not attempt to (Larkin et al., 2006).

One way of acknowledging and being aware of one's own preconceptions and bias, and the connection between these and the research, is to provide a reflexive account of the researcher's self and the impact this has on the data analysis and the general research (Denscombe, 2007). Berger (2015) describes reflexivity as "...the process of a continual internal dialogue and critical self-evaluation of researcher's positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome" (Berger, 2015, p. 220). This recognition is crucial for the researcher and for the data, as a researcher who does not reflect over their own role in the research and the interpretation of the data is doing both themselves and the research a great disservice, and the study will suffer as a result.

The hermeneutical nature of IPA analysis makes researcher reflexivity especially important. Smith and Osborn (2008) state that a researcher following the IPA method draws on their own interpretative resources to make sense of what the research participant is saying, but is at the same time checking their own sense-making in relation to what the participant actually said. This is difficult to do if the researcher has no awareness or insight into their own position and biases, as these will undoubtedly affect the 'sense-making'.

To reflect on one's own biographical presence within the research is not only a way for the researcher to make a conscious and deliberate effort to be aware of one's own reactions and construction of analysis, but also helps the researcher to maintain the awareness of themselves as part of the world that they are studying (Berger, 2015). For this study, I attempted to apply reflexivity at all stages of the study; before data collection, during the interview phase, and during analysis and writing up of the study.

Before I began the field work, I was aware of the complexities involved in dealing with a population with a cognitive impairment, while at the same time not having had any previous direct experience of this particular population. Prior to starting the PhD, I had worked as a research assistant on a number of different projects involving older persons, and persons with dementia, but I had not been in a position where I was the main researcher making fundamental decisions about the course of the research, how that may affect both the future participants, and the path the research would take. I also had to acknowledge that I was an able-bodied, young, well-educated woman with no cognitive problems and no experience of dementia in my extended family – this meant that I may not be as attuned to nuances and

emotions from the participants as may be necessary. Also, it was important to keep in mind the fact that as a foreigner, albeit one who had lived in Ireland for a long time, I may not be fully aware of cultural stigma of dementia or all social cues around it.

Throughout the recruitment and analysis phase, I kept a “research diary” where I wrote down my thoughts and impressions after each interview, and anything else that felt relevant or important. I did this partly to help re-create the setting in my mind (the feeling of the house, the conversation outside the interview, body language, and so on) but also to describe any strong feelings I had. This was useful in a number of ways, as it gave a multi-faceted picture of the participants at the same time as I was able to return to my initial reactions and compare them with my interpretations during analysis. For example, often my main feelings after an interview tended to be awe at the resilience of the participants, and deep gratitude for the grace and generosity that they had shown in openly sharing some of their most private and difficult thoughts and experiences with me. However, through the analysis it became clear that while my feeling of awe was not incorrect, it risked reducing the narrative to an overly simplistic ‘sick person overcomes obstacles to live happily ever after’-story. This was not reflective of the participant’s lived reality, but rather it was a reflection of an innate compulsion which I have always had to find a happy or positive angle to all things. Being aware of this, and reflecting on how it affected my analysis, made me more cognisant of the importance of continuously checking back with the original transcript and keep the chain of continuity intact. In this way, the reflexivity practice, combined with also reflecting upon the interpretative framework applied to the data, helped increase the transparency and the awareness of the analysis (Storey, 2007).

The above example illustrates why researcher reflexivity is so important. Also, as we are often not aware of many of our preconceptions, it was necessary to keep up the reflective practices throughout the analysis stage (Smith et al., 2009). Dodgson called the practice of researcher reflexivity “...a process of expanding one’s consciousness to make what has been tacit explicit” (Dodgson, 2019, p. 221). This sentence summarises the reflexivity practice very well, in how that which is hidden in the researcher’s biographical presence needs to be brought into the open, so as to ensure that the researcher is interpreting the data in the most authentic way possible.

3.3.6 Ethical approval

Ethical approval for the study was applied for and approved by the Research Ethics Committee of the School of Social Work and Social Policy, Trinity College Dublin, on 21 January 2013.

Gatekeepers used to recruit participants did not require any further ethical approval, except in one instance. An application for participant recruitment was made to and approved by the Research Ethics Committee of a university hospital (anonymised).

3.4 Recruitment

3.4.1 Sampling

Participants were sought out through purposive sampling: this was line with IPA's orientation towards insight into a particular experience (Smith et al., 2009). Purposive homogenous sampling is not the same as treating members of a certain group as identical to each other, but rather a way of enabling the researcher to analyse the patterns of convergence and divergence within a group experiencing the same phenomenon.

The specific number of persons to participate in the study was left quite open. The aspiration was to reach some form of saturation point in the data collection, meaning that the numbers of participants would be dependent on at what point no new insights were emerging. IPA studies tend to have a relatively small sample size, as the aim of the analysis is to do justice to each case and the detailed nature of the IPA analysis of data pertaining to each individual takes a long time; the norm for an IPA study is around six to eight participants, however this does not mean that more or fewer participants is in any way incorrect or not compatible with IPA (Smith & Eatough, 2007). In this study, the final number of participants was ten.

As men are more likely to get young onset dementia than women (Cahill et al., 2012), it was expected that this would be reflected in the gender composition of the sample. Nevertheless, every effort was made to keep an even gender balance, as women and men may have different experiences of the illness and this was very important to capture. The sample consists of six men and four women.

In addition to this, I wanted to purposively sample for some participants who have children, either under 18 years of age or young adult children. Having children is often an issue with YOD, affecting identity, roles, relationships and changes in independence between the child and the parent with YOD; children may also be offering support and care to their parent

(Svanberg et al., 2011). Among the ten participants, seven had children, with an age-range from mid-teens to late 20s.

3.4.2 Inclusion criteria

In order to be able to participate in the study, a diagnosis of YOD was a prerequisite. YOD is generally defined as someone under the age of 65 with dementia (Johannessen et al., 2015). While this cut-off point of 65 years old is quite arbitrary, it tends to be the traditional cut-off, or indeed starting point, for many services, based on the (also rather arbitrary) conventional retirement age of 65 (Chaston, 2011). The age-specific nature of the definition of YOD as being a person specifically under 65 years old is largely due to the fact that dementia is viewed predominantly as a condition of older people (Harvey et al., 1998), and the relative 'youth' of the person with the illness sets them apart. In addition to having a diagnosis of YOD, another inclusion criterion was for the person to have had their diagnosis for at least one year. This was to allow for sufficient time to have passed since diagnosis, and for potential interactions with health care and social care services.

Further, in order to be deemed eligible to participate, the person's cognitive ability had to be of a level where they could understand what the study was about, what it entailed, and could consent to participate independently. This was particularly important, as it would be highly unethical and contrary to all research ethics principles to include someone who did not know what they were being asked to do, and why. I therefore had to employ all of the procedures described in section 3.3.2 (Informed consent) and 3.3.3 (Interviewing a person with dementia), to ascertain that the potential participant had this level of cognitive ability. Finally, if at any stage there was any doubt as to whether the person was not able to consent, it was my responsibility as the researcher to terminate or disregard the interview. As will be discussed below, this happened on two occasions.

3.4.3 Gatekeepers

Rather than relying on direct recruitment, I decided to use gatekeepers to recruit participants. The main reason for recruiting through gatekeepers was that they provided a better assessment in relation to the abilities of the participants, and provided assurance that unsuitable or inappropriate recruitment would be avoided as much as possible. Not only were the gatekeeper professionals, used to working closely with persons with dementia, but because of their relationship with the person they knew them better and were in a position to

assess if a person who fitted the recruitment criteria also had the cognitive ability to independently and freely consent to participation.

Participants were recruited by approaching gatekeepers such as staff at Memory Clinics and advocacy organisations for dementia. Memory Clinics were chosen as many cases of YOD are diagnosed there as opposed to with the GPs, as YOD is generally harder to diagnose due to the person falling outside the expected age group. Also, YOD is often caused by a rarer subtype of dementia, which can be more difficult to diagnose and is therefore more often referred to a Memory Clinic. I also put advertisements in newsletters and through appropriate social media to source participants, as well as putting up posters seeking participants in suitable locations, such as in for example Alzheimer Cafes. Of the ten participants in the study, seven were recruited through gatekeepers from two hospitals' Memory Clinics, and the remaining three through gatekeepers in an advocacy organisation.

3.5 Data collection

3.5.1 In-depth interviews

The most suitable data collection method for an IPA study is in-depth interviews, as interviewing invites participants to offer a rich, detailed first-person account of their experiences, and allows them to fully express themselves. In-depth interviews facilitate understanding the participants' perspectives on their lives, experiences and situations, expressed in their own words (Kumar, 2005; Smith et al., 2009). In-depth interviews are particularly well suited to research that requires an understanding of responses to complex processes or experiences because of the depth of focus and the opportunity for clarification and detailed understanding (Ritchie, 2003). For the semi-structured in-depth interview schedule for this study, I developed the questions that made up the interview schedule together with my supervisor, to ensure all angles were covered. In IPA, research questions tend to be framed openly, broadly, and with an aim to explore a topic in detail, but still flexibly (Smith & Osborn, 2008). This flexibility and openness was maintained in the interview schedule, which can be found in Appendix C.

In this study, five participants out of a sample of ten had their partner present during the interview. The Information Sheet for the study was directed to the person with dementia only; while not expressed in writing, spouses or partners were welcome to attend if the person with dementia wanted them there. Three of the participants felt more comfortable with their

spouse or partner present; in one case, the person with dementia had travelled from another part of the country to meet the researcher and their partner was present; in another, the partner was present part of the time but left to walk the dog for the majority of the interview. It was up to me as the researcher to ensure that the person with dementia was given every opportunity to have their opinions and voice heard during the interview despite their partner being present, and this was something that I was very conscious of throughout the interviews.

The interviews took place at a location that suited the participant. Of the ten participants, seven were interviewed in their home, one in respite care in hospital, one in their place of work, and one in a venue in Trinity College Dublin as the participant had travelled from their rural home to meet with me. The interviews were recorded on a Dictaphone, and I transcribed the interviews verbatim without using any software. The transcribed interviews were fully anonymised and stored in password-protected files.

3.5.2 Participants

In total, 12 participants were interviewed for this study. Two were excluded due to lack of cognitive ability (see section 3.5.3 Excluded participants below for more information) meaning that the final number of participants was ten persons. All names are pseudonyms.

Table One below gives an overview of the participants and their main demographic information.

Table One: Participants

Pseudonym	G	Age	Area	Urban /rural	Education	Marital status	Children	Employment
Margaret	F	62	North-west	Rural	Upper secondary level	Married (spouse David present at interview)	One daughter	Retired before illness
Sean	M	58	East	Urban	Lower secondary level	Married (spouse Aisling present at interview)	Two sons, one daughter	Not working at time of diagnosis; did not seek new employment due to illness
Micheál	M	62	North-west	Rural	Third level degree	Married	One son	Retired because of illness
Seamus	M	59	East	Urban	Third level non-degree	Living with partner (partner Bláthnaid present part of interview)	No children	Retired because of illness
Fintan	M	57	East	Urban	Third level degree	Married	One daughter, one son	In employment
Fionn	M	57	East	Urban	Third level degree	Married (spouse Maeve present at interview)	No children	Retired because of illness
Orlaith	F	54	South	Rural	Upper secondary level	Separated	Two sons	Not working because of illness
Niamh	F	54	South	Urban	Third level degree	Single	No children	Retired because of illness
Tadgh	M	56	West	Rural	Lower secondary level	Married (spouse Caoimhe present at interview)	Three sons	Retired because of illness
Noírín	F	65	West	Rural	Third level non-degree	Married	One son	Retired before illness

3.5.3 Excluded participants

Two participants who were interviewed for the study were excluded from the study. This decision was taken during the interviews, as I realised that their level of cognition was not sufficient to be able to participate.

Both participants, one man and one woman, had been recruited by the same gatekeeper, a consultant clinician at a private hospital. She had spoken to the two people, and asked me to come in and meet with them and set up the interviews to take place on the same day. The first interview took place in the morning with a male participant. The participant was very kind and happy to participate, confirmed he understood everything and was eager to speak about his experiences. However, throughout the course of the interview it became clear that he was not as cognitively capable as he first seemed – he did not know why he was in hospital, he did not know what I meant when I asked during the interview about participation, and at one stage asked me if I could tell him what was wrong with him, how long he would have to stay in the hospital for, and when he could go home. I concluded the interview early, and decided that while the man was eager to participate, it was clear that including his interview in the study would be unethical – he did not know where he was, he was not aware that he had dementia, and he was not able to understand his participation. The second interview, with a female participant, was even more problematic. She seemed very ill at ease from the beginning, was not able to answer basic questions, and the interview consisted of the participant saying random sentences and repeatedly asking if she could go for a cigarette. It was quickly obvious that it would be inappropriate to include her in the research, as she had so little awareness, and I stopped the interview within five minutes.

The consultant clinician told me that these participants had good days and bad days, and that maybe another time would work better for an interview. However, I felt it would be inappropriate and potentially distressing for both persons, especially the female participant, if I came back and attempted to interview them again. Both were therefore not contacted again, and their interviews were excluded from the data. This experience with the two excluded participants highlighted how on occasion the gatekeeper and the researcher can have diverging opinions; in this case, I decided to follow my instinct and not contact the two participants again, despite the gatekeeper's assertion. The gatekeeper was a healthcare professional with extensive clinical knowledge, however as the researcher I felt it was important to follow my own opinion, regardless of the gatekeeper's expertise.

3.5.4 Levels of insight and ability of participants

The level of insight of the participants included in this study was generally good, however it varied between participants. This is reflected in the length of some of the interviews compared to others, and the level of language skill, the ability to make an argument, or to analyse a situation or discuss a problem. The shortest interview was 26 minutes long; the longest was one hour and 40 minutes. The majority of interviews were around one and a half hours long.

The two participants with the lowest level of insight, Seamus and Tadgh, were able to freely consent, and could participate and follow the conversation, but in different ways. Tadgh's wife Caoimhe was present throughout most of the interview, except for a 20-minute segment when she left to give one of their sons a lift. During the interview, Tadgh varied between paying attention and adding comments for comic relief, to not paying attention at all; he came across as bored a lot of the time. He nevertheless was able to speak for himself in his own way, and answered questions when he wanted, and when Caoimhe was away he was able to have a free-flowing, albeit at times limited, conversation.

Seamus came across as quite subdued, and when his partner Bláthnaid left to walk the dog, leaving us alone for the majority of the interview, he was initially quiet. Before his illness, Seamus had been very politically active and involved in social justice, advocacy, and participated in both local and national demonstrations and events. He was eager to participate in the interview as he wanted to be part of research and share his experience, and he was also involved in a research project in another university. However, he was struggling quite a bit with his speech, and it seemed difficult for him to put his thoughts together in a sentence and then get the words out. He was quite obviously frustrated about this, but nevertheless persisted in speaking, albeit in a soft, slow way with many pauses. I was still able to gather information from him, and he was very generous with his time and came across as very pleased that he was able to participate and be included, despite his initial silence and difficulties speaking.

Micheál had better insight than Tadgh or Seamus, but his insight was still limited. He was interviewed in a hospital where he was in for respite care, and while he was pleasant and friendly, he also seemed a bit bemused and slightly exasperated by the interview process. He spoke very well, but his answers were short and he made it quite clear that he did not have much interest, or capacity, in delving too deep into any area of questioning. He was able to express emotion and understood everything that was being asked, however he did not seem capable of speaking for long. I had met him on a previous occasion to give him an information

leaflet and ask if he was interested in participating, and on that occasion everything he said was in rhyming verse. On the day of the interview, however, his speech was more contained and he did not seem to have any wish to engage in more in-depth participation.

Margaret, Sean, Fionn and Niamh all had a good level of insight, and had no problem speaking or answering questions and expressing their thoughts and concerns. Margaret, Sean and Fionn had their spouses with them, and all were at times happy to let the spouse speak for them. However, I made an effort to specifically engage with them and not only with their more communicative spouses. At times, the participants were holding back a bit but this may not necessarily always have been as a result of their dementia. For example, Sean tended to look to Aisling for agreement before and while he spoke throughout the interview. At one stage Aisling described a meeting at the Memory Clinic where Sean had looked to her to speak the whole time and she had felt compelled to explain to the doctor that this was a habit that he had had throughout their marriage – Sean was dyslexic and had always let Aisling deal with anything involving professionals, preferring her to deal with such things, and this was the same in the interview. Niamh had a good understanding and was able to communicate well, if somewhat vaguely at times. She had written a short summary/bullet point list before the interview, which she consulted during the interview and read out towards the end, to ensure that everything that she wanted to bring up was covered.

Orlaith, Fintan and Noírín all had an excellent level of insight, and a highly sophisticated level of analytical and linguistic ability. All three were quite heavily involved in dementia advocacy which came as no surprise, given how well they were able to outline their concerns and communicate their thoughts and experiences. They had a level of insight and above all a verbal dexterity which made their interviews especially detailed and insightful. This is not to say that the other participants' contribution was not insightful, but rather that Orlaith, Fintan and Noírín communicated especially well.

3.6 Data analysis

The area of questioning in this study was around the experiences of persons with young onset dementia, relating to their interactions with the health care and social care services, but also their experiences in general. The interview schedule was divided into three sections, with the first dealing with diagnosis, the second one with services, and the third with the impact of dementia on their lives. The ten interviews produced a huge amount of data, and IPA methodology was used to analyse this data.

The IPA method of analysis allows for learning about the important generic themes in the analysis, but still maintains the individual narrative world of each participant (Smith & Eatough, 2007). Unlike some analytical methods, IPA does not have a strict prescriptive approach to analysis, but instead provides a set of flexible guidelines to be adapted to both the research aims and the analytical process (Smith & Eatough, 2007). The systematic data analysis informed by IPA and carried out by the researcher will be described below.

I began the analysis of each interview by transcribing the recorded interview. Transcribing interviews verbatim is a time-consuming and drawn-out process, and the slow pace of transcription can at times make it feel insurmountable. However, what can be overlooked in relation to how long transcribing takes, is the great benefit of how close it brings you to the interview and to the participant. Throughout the transcription process, I became even more familiar with for example a change in the tone of voice, a particular use of a word, a meaningful pause or shifting emotions – these can be obvious in the face-to-face interview, but they can also be fleeting and almost imperceptible, and only become clear with further familiarity with the interview.

Once each transcript was completed, I read and re-read it, to further acquaint myself with the text, and then made preliminary analytical notes in the left-hand margin of the paper, creating initial codes. These notes covered all that I found to be noteworthy, significant, interesting or unusual – they were the basis for initial interpretation, connection-making, and served to give a sense of the particular person being interviewed (Smith & Osborn, 2008). While doing this initial noting, I heeded the advice of Smith and colleagues who suggested interpretative noting with a clear phenomenological focus, and to pay particular attention to three processes: i) Descriptive comments – focused on describing the content of what the participant has said, the subject of the talk within the transcript ii) Linguistic comments – focused upon exploring the specific use of language by the participant iii) Conceptual comments – focused on engaging at a more interrogative and conceptual level (Smith et al., 2009, p. 84).

After completing this initial note-taking, the next stage of analysis involved returning yet again to the transcript, and this time reviewing the notes/codes that had been made in the left-hand margin to produce themes in the right-hand margin (Storey, 2007). This was made with overall themes in mind, but also much of the analytical focus stayed on the individual interview, as each participant described different and unique experiences. While it was expected that common themes would be found, I felt that it was still of great importance to identify,

acknowledge, and include themes and experiences that were unique to only one participant, where relevant.

At the end of each transcript, I attempted to organise superordinate themes into a table, where they were listed together with related sub-themes (Storey, 2007). In analysing the data and trying to make sense of it, I tried to look at the data critically, empathically, and, as per IPA, with a questioning hermeneutic (Smith & Osborn, 2008). As the data collection took place over the space of nearly two years, the interviews were transcribed and analysed over this time. This meant that I was constantly reverting back to the transcripts, continuously re-reading and re-familiarising myself with the transcripts. I initially analysed each transcript in isolation before comparing them to each other, to ensure that the individual core of each participant would not get lost; and through these exercises the thematic table grew, changed, and developed over time.

Throughout the analysis, I tried to stay truthful to each person's unique experience, while also trying to interpret what their experience meant. Smith and Osborn describe this balancing act eloquently:

"IPA has a theoretical commitment to the person as a cognitive, linguistic, affective and physical being and assumes a chain of connection between people's talk and their thinking and emotional state. At the same time, IPA researchers realise this chain of connection is complicated...the researcher has to interpret people's mental and emotional state from what they say" (Smith & Osborn, 2008, p. 54).

Throughout the process it became apparent where a connection of the superordinate themes between the interviews existed, and overarching themes connecting the interviews developed. I used NVivo software to keep track of all emerging themes and subthemes, however at times the software felt intrusive and overly complicated, and I often went back to the very basic tools of paper-and-highlighter combination during analysis. Nevertheless, NVivo acted as a backup for organising and keeping track of themes, and was always useful to fall back on to get an overview of the themes, or to easily find a quote.

Shaping the analysis into a narrative account in the form of the Findings chapters was a challenge. Summarising the themes and describing, explaining and putting them into context while at the same time keeping a clear line between the words of the participant, and the interpretation and analysis by the researcher, demanded a clear vision and strong structure (Smith & Osborn, 2008). Another difficult aspect of the data analysis was to streamline the

superordinate themes and decide which ones to focus on, and which ones not to include. The careful and detailed analysis that went into each transcript meant that very many themes and/or events and experiences felt vital to the person's story, and to their overall experience of life with young onset dementia. As themes are chosen not on their prevalence within the data, but rather on the richness of the account, and how it might illuminate other aspects of the participant's experiences (Smith & Osborn, 2008), I found it difficult to not include some experiences or themes in the write-up. However, it was obviously not feasible or even conceivable to discuss all of the data (Denscombe, 2007). It was at this stage that I fully understood why a study that uses IPA methodology cannot have a large sample size, as the analysis is simply too detailed to be able to include everything satisfactorily, and still do the data justice.

With the analysis completed and the themes fully developed, interlinked and reconnected to the data, the subsequent phase of the project was to begin writing the Findings chapters. These ended up being split into three chapters according to thematic areas within the data; the first on healthcare and disclosure of diagnosis, the second on societal experiences of living with YOD, and the third one discussing the personal sphere of YOD.

CHAPTER FOUR – FINDINGS AND DISCUSSION I: PATHWAY TO DIAGNOSIS AND DISCLOSURE OF YOUNG ONSET DEMENTIA

The following three chapters contain the findings from the qualitative interviews carried out for this study. An overview of the participants, as well as a more in-depth description of their abilities, can be found in *Chapter Three: Methodology and Methods*. The interview schedule used can be found in Appendix C. The first Findings and Discussion chapter looks at the pathway to care experienced by the participants, the diagnosis and disclosure process, and the period after diagnosis.

4.1 Introduction

The pathway to care for the participants of this study started with the onset of symptoms which unsettled, confused, or bothered the person, or at times a family member. Most participants turned to their GP as the first port of call, however, the pathway from there to diagnosis was generally not straightforward, and the variety of symptoms and the failure to even suspect dementia was often an issue. This chapter looks in detail at the participants' symptoms and what made the person seek help. This is followed by the participants' experiences of their interactions with the medical world, their navigation of the health care system, and the disclosure process. Finally, the immediate post-diagnosis period is analysed.

4.2 Symptoms

Stress, caused by a wide array of issues, was initially believed to be the culprit for many of the changes experienced by the participants. Sean, a middle-aged married man in a large city, was having ongoing problems at work where the company he worked for were trying to terminate his contract unlawfully. The stress of this situation, and a subsequent court case for unfair dismissal convinced his wife, Aisling, that the shock of all the troubles brought on his Alzheimer's:

A: I'd say about ten months after he lost the job we'd be sitting having conversations and in the middle of the conversation Sean would lose what track of what he was saying, he'd know what he wanted to say but the words just weren't articulating...[I] put it down to the stress of the court case coming up, and [son and girlfriend] were up here one night having a few drinks with us, we found ourselves finishing the sentences for him, about half the time we weren't getting it right so we were making him even worse [laughs] so [girlfriend] joking turned around to me and said 'this is like playing

charades', and that struck a chord with me then, and I said this isn't getting any better, and I wasn't convinced then that it was stress, that there was something else going on.

This experience prompted Aisling to organise for Sean to go to his GP. The loss of Sean's job and the court case had been difficult for the whole family, with Aisling taking on more shifts at work to ensure financial stability, and all feeling anger and sadness at the unfairness of the treatment Sean had endured. The stress they were living through had both masked and excused Sean's difficulties finding words and expressing himself, until it was apparent that stress could not be the sole reason for the problems.

Caoimhe and Tadgh are a married couple living in a rural part of Ireland with their three sons. Caoimhe described her husband Tadgh's symptoms briefly but succinctly:

C: The first thing was not seeming to care about anything, no, I think apathy is the word they use to describe it, not caring about the garden, not caring about what the house looked like or what I looked like or what he looked like or, and then the, the biggest thing probably was the bills not being paid up to date, so they were the two biggest things.

An accumulation of issues eventually prompted them to seek help:

C: I thought first he's, that it was depression, because it was the lack of, he loved the garden, and he stopped, I mean there just was, weeds and bits of trees and, we used to have a dog he died about three weeks ago, and there were empty cans and you know, he'd feed him and throw the can, and it was like oh my God, like, even friends of mine, one particular girl she says don't take this wrong way she said, but I never saw your garden such a mess, it is not like Tadgh, you know there was a lot of that kind of thing, and when I point it out to him, 'ah what can I do', and I go 'well you can go out and do it', but I remember saying to my sister I hope and pray it is only depression.

The change of personality visible in Tadgh was affecting the whole family, and depression seemed the obvious reason behind his change. While not a happy diagnosis, depression was still preferable to Caoimhe than whatever 'it' might be – perhaps more severe mental health issues, brain tumour, or dementia – showing the immediate stigmatisation surrounding even the suspicion of dementia.

Fionn and Maeve are a married couple living in a large urban area. Like for Tadgh and Caoimhe, when Fionn started noticing changes in his behaviour both he and his wife thought it might be related to mental health.

F: one of the first things, was when I was taking phone calls, so people would talk to me and I wasn't able to take in all the stuff, you know, that was going on for a long, for a while you know...I was aware that I was asking people you know once, twice, maybe three times, you know what I mean, that was the first time, but I never, I knew something was wrong, not, I wouldn't have, at the time I wouldn't have said there's something wrong, it, I probably, at that time I was thinking I'll have to do something about this, you know

Fionn thought his forgetfulness was due to a past history of mental health problems, as Maeve explained.

M: Fionn suffered with depression before, so he was inclined to think it was anxiety, and, the first time I went with you, you had gone before and you had mentioned to [GP] about missing words...you were worried and I had noticed a couple of things that I couldn't explain, and I wouldn't have associated with dementia at all, you know, Fionn having difficulty doing things, and we went to the GP together and [the GP] was inclined to say it was anxiety...

Fionn was also having difficulties with tasks such as getting parking tickets, and was experiencing problems with words that simply would not come, or he would skip words in sentences. Regardless, the GP put it down to anxiety, probably as a result of Fionn's previous experience of depression. However, it is worth noting that many GPs are reluctant to diagnose dementia because of the lack of a cure and perceived hopelessness of the illness. Also, many GPs simply lack the skills or tools to make an initial diagnostic investigation for dementia.

Problems at work caused by symptoms of dementia was the catalyst for three other participants realising something was wrong. Micheál, a married professional from a rural area, used coping mechanisms to get around his difficulties:

M: I was finding it very, very difficult to deal with files in the office, I didn't remember anything, now any clients who came in, I insisted that the receptionist down at the door would tell me the name of that client so that I could go and get the file and look at it, just to have a general idea...

Micheál's family had also noticed changes, and got him to visit the local GP. A resolute and straightforward man, his coping mechanisms had enabled him to keep working and functioning to a certain extent, however this came at a professional cost, as will be discussed further in the final discussion chapter. As he did not share with anyone that he was having

issues remembering what his clients were there for, his coping mechanisms could only function for a limited time before cracks appeared.

Niamh, a single woman in a small city, was having trouble at work but while she knew something was not right, she kept going, and trying her best:

N: ...I hadn't a clue [about symptoms] but I was not performing good at work...I started noticing that I couldn't use some of my fingers, just didn't seem to go where they should be going, and I just didn't know what to, what it was...I got regular bollockings for want of a better expression [laughs] whatever, and then you know, that went on for probably quite a while...

While Niamh's colleague and boss encouraged her to see a doctor and eventually sent her to the company doctor, it was her sister-in-law who, having noticed changes, got her to see a doctor which started the process of diagnosis.

N: ...roundabout last Easter my sister-in-law came up to me...I've always played golf and tennis and things like that but...I called [nephew] and asked him would he shown me how to do the [tennis] scoring again...I saw my sister-in-law kind of staring at me...she was just kind of watching me you know and I hadn't really ever noticed her doing that before but she, she came along then a few days later and she, you know, she's a very blunt lady and she said what the fuck are you at [laughs].

On top of her work troubles, Niamh was struggling with sequential tasks and was also behaving impulsively and without consideration. For example, she had been in a very minor collision with another car, caused by the other driver – but instead of exchanging details and ensuring that the other driver pay for the damage caused by the collision, she agreed to the other driver's suggestion that he take her car with him and fix the damage himself. She got her car back with the damage repaired, but it took longer than expected and for a while she did not know if she would get the car back; and she could not explain to herself or her sister-in-law why she had agreed to simply hand over her car to a complete stranger. This type of conduct was out of character for Niamh, and her sister-in-law called out her changing behaviour, until it was not possible to disregard it anymore.

For Fintan, a married man in a large urban area with two children, the stress he experienced in work revealed that not everything was as it should be.

F: ...I had just completed a period...in an extremely busy and stressful job, which took a lot out of me and I was really, you know, tested by it...I think what that stress did was, it exposed, it exposed the small dysfunctions that were emerging.

He had taken up a new job as a general manager covering parental leave in a position which was very demanding and intensely stressful. He was dealing with many challenges and was learning on his feet – this was familiar to him from his job in the arts world, and he described it as *“the old music hall variety act, the spinning plates on top of the stick”*. On one particular day, he had a number of very urgent things to deal with and in the midst of it all he was collating papers to send off that day, but he kept on getting interrupted and every time he went back to the papers, he simply could not complete the task. He had experienced some difficulties leading up to this with retaining information and had noticed his efficiency had gone down, but on this particular day with the papers he knew that *“there was something that just wasn’t working”*.

These experiences from some of the participants present a picture of general confusion and uncertainty as to what was causing the issues they were experiencing. Whether the issue was apparent at work and coping mechanisms used to try to cover up, or if the person did not address the issue but a spouse or family member noticed it, dementia was not generally at the forefront of the person’s worries. Instead, the interactions with medical professionals to try to find out what was going on were more exploratory as opposed to a firm suspicion of dementia – and as we will see, this was often the case for the medical professional too.

4.3 Interaction with medical world

This section will focus on the participants’ experiences of the period leading up to diagnosis, of dealing with healthcare professionals, and the back-and-forth between clinics and specialists that many experienced.

When symptoms or concerns had caused the participants to seek medical help, their GP was the first port of call for the majority, however after that the pathways to diagnosis were many, different, unclear, and uncharted. For Tadhg, his interactions with the medical world were frustrating and confusing up to and including the diagnosis. After about three to four months of symptoms which could no longer be ignored, Tadhg went to the doctor to see what was causing the changes in his behaviour. The first visit yielded no results, as the doctor could find nothing wrong:

C: [Tadgh] agreed to meet him, met him, and of course looked fine, answered everything appropriately, and it was fine, and then I rang the doctor again and he goes nah I don't think there's anything, you know, was he a bit tired or, so did a bunch of blood tests eventually.

The blood tests only revealed that Tadgh had low levels of testosterone. They went back a second time, and Caoimhe brought with her notes she had taken of all the “odd behaviours and lack of caring”. The GP did more blood tests but nothing was found, so finally Caoimhe decided to change tactic:

C: ...the third time I made up a lie and I said he's getting dizzy and severe headaches [laughs] so he had an MRI brain scan based on that... at half 8 in the morning, and at 12 o'clock the same day the GP rang me with the results.

The results, read out by the GP over the phone, were a significant atrophy in the frontal lobal and temporal part of the brain. While this was a diagnosis, disclosed bluntly over the phone, they were left to keep looking for more answers alone, and the quest for suitable care and information continued. In light of the test results, the GP had referred them to a geriatrician/stroke specialist in a nearby city, who carried out tests such as the Mini-Mental State Examination (MMSE) and clock drawing test, which Tadgh scored well in. They went twice, at a cost of €150 each time for the private clinic, and Caoimhe was wondering what the next step was:

C: ...and I kind of said, like, what good is this type of thing, now [geriatrician] was really nice, he was, he said I admit my knowledge is limited, I'm mostly like an old person's doctor or a stroke or somebody with AD so he said there is a centre in [large hospital in major urban centre] and it is there the centre for excellence for dementia, and it is free and I will refer you there, so we had to wait I think until July, June or July

The geriatrician did not know how to deal with 56-year old Tadgh, or his type of dementia. At the Memory Clinic, a thorough examination was carried out and a diagnosis of probable behaviour variant frontotemporal dementia was finally made. The journey to diagnosis had been confusing, involving primary care, scans done privately and visits to a geriatrician also done privately. Caoimhe had been very proactive in finding a solution to the problem, and the referral to the Memory Clinic was what finally helped them. However, Caoimhe felt that help, or even simple information, should have been available at an earlier stage: “the one thing I

would have liked is if the GP had known more about it, you know, I felt I was telling him based on what I had read myself... but from once I found [the Memory Clinic] I was like phew, now."

Similar to Tadgh, Fionn also had to visit a number of different health care providers to get the answers he was looking for. While Tadgh lived in a very rural setting, Fionn lived in a major urban centre with a number of the country's top hospitals close by; nevertheless his route to diagnosis was also roundabout and unclear.

When Fionn together with Maeve first went to see their GP, the doctor thought Fionn's issues stemmed from his previous history of depression and anxiety, and did not really look any further. Both Fionn and Maeve had to emphasise how worried they were to get the GP to see past the depression/anxiety issue:

M: ...I kind of pushed the GP on it, and he said well if it is still the same in three months come back, but then he asked Fionn to draw a clock, and, you weren't able to do it... and he got worried then...

The GP referred them on to a Memory Clinic located in a major hospital, where Fionn received a diagnosis of YOD. The whole process had taken around 18 months, from when they first went to the GP with their concerns to when the diagnosis was given. The 18 months had been spent going back and forth to the GP, seeking psychiatric help privately, and waiting for appointments. Fionn and Maeve described the 18 months as a very tough time, where uncertainty and confusion was constantly present. During this time, they moved to a new house and rented for a period in between, which both exacerbated and accentuated the issues Fionn was experiencing:

M: I think your symptoms were kind of, either they were getting worse or we were getting more aware, becoming more aware...

F: probably a bit of both I would say.

Throughout the 18 months, they continued to try to figure out what was wrong with Fionn. Their GP suggested they go to see a psychiatrist, which they did, with mixed outcomes.

M: and like the GP was still, because do you remember we went to, he recommended us to go to the psychiatrist, do you remember Dr X?

F: oh God... [both laugh] he was...

Interviewer: a bad one?

M: [laughs]

F: no, he was, well he was, very, very, VERY old

The psychiatrist did help them in terms of adjusting Fionn's anti-anxiety medication and antidepressants, however he was, as Maeve described him, "...very old school..." and did not seem to take their concerns very seriously. Fionn and Maeve saw him on a number of occasions, paying privately for the visits. The psychiatrist, however, was telling them the opposite of what they were being told by the Memory Clinic.

M: the last time we went in and it was what, €120 for the repeat visit €240 for the first one but anyway, we went in, this was like the third or fourth visit, and the two of us went in and Fionn sat down, and he looks up and he says to Fionn well you look better [F laughs] do you feel better, now you look, we've hit the spot with the medication, they are not going to find anything in the Memory Clinic with you, and we were in the car park before we knew where we were again, like we were in and out like that [snaps fingers]

While the story of Dr X was retold with a lot of laughter, there was also a sense of frustration as to the length of time everything took, and the stress and worry that they lived with during that time.

Sean had a more straightforward experience of his initial interaction with the medical world. Together with his wife, he went to their GP who carried out a few tests and referred them directly to a Memory Clinic located in a major hospital. Aisling describes their consultation with the GP:

A: ...it's like this he says, 'I'm going to refer him somewhere' he says, 'it was like dealing with an old person in a young body', so that was ok, fair play to our GP he gave us a consult for every hospital to see who could get to him the first, because we don't have private health insurance...

By referring them to two hospitals, the GP shortened the waiting time which was very helpful, and by referring them straight away to Memory Clinics they were able to get the expert diagnostic care they needed. Sean and Aisling were both very happy with their experience in the first Memory Clinic they attended, both with the support they got and with the personal chemistry:

A: ...Sean got on great with [doctor], I could see from the very beginning when he was doing the test and all with him, he was great with him, he felt really, really comfortable...

In the meantime, another smaller Memory Clinic got in touch with a time for a PET scan, and as this was for an earlier date than in the first Memory Clinic, Sean and Aisling decided to go ahead with it. The first Memory Clinic got a copy of the PET scan and was able to give them the diagnosis. They were told together, and Aisling, who works as a health care assistant, had an idea at this stage what was happening.

A: ...[doctor] was after telling us that he thought it was one of two things, but he didn't mention them but in my mind there was two things, and that was Parkinson's and Alzheimer's, and I'm a health care assistant myself so... I won't say I was shocked, I can't say I was shocked...

It was difficult for Sean to take the information in, which the doctor noticed:

A: ... [the doctor] turned around to me and said I don't think Sean is taking this in, and I said he is, I tell you now he is, but looking back on it now I'm not convinced he did, as time goes on now I'm not convinced it did sink in with him, but I thought because his mother had it, that he'd realised what had been said to him.

Sean describes it as just not getting into his head: “...I didn't, I didn't think in my head even you know, and that was it...”

After receiving the diagnosis from the first Memory Clinic, they were nevertheless called to the second one to get the results from the PET scan. After discussing it with the doctor in the first Memory Clinic, they decided to go along to the meeting, but they would remain as patients in the first Memory Clinic as Sean had already been enrolled in a clinical trial there. This proved to be a good decision, as they were not happy with the treatment they received in the second Memory Clinic. When they had gotten the PET scan done there was no rapport with the doctor – rather, it was the opposite: “...I could see there was no bond there with Sean whatsoever, Sean didn't like him, I knew he didn't like him, he wasn't comfortable with him, he was a bit aggressive in his questioning of Sean...”

When they came to get the diagnosis, the original doctor was not there but one of his registrars, who gave them the diagnosis and then left them to fend for themselves:

A: ...we didn't get the backup and I said thanks be to God we knew when we were coming in here...he just told [us] and that was it, goodbye...there was no backup, social worker...or anything, nothing, and I said thanks be to God we stayed with [first Memory Clinic]

In the first Memory Clinic, the doctor had ensured that supports were available when they received the diagnosis in the shape of the clinic's own social worker. Having a social worker present, who is specially trained to deal with people in distress and who also has detailed knowledge of what services are available, what the more practical, non-medical next steps are, and what supports are needed, was hugely valuable. Aisling described it as the first Memory Clinic having the social worker '*waiting in the wings to pick us up*', which indicates the importance of such support.

Like Sean, Fintan was referred straight from his GP to a Memory Clinic. Fintan had experienced his father getting dementia and recognised the signs in himself, and while his GP thought he was a 'worried well' person he nevertheless took Fintan's concerns seriously and gave him the referral he asked for. Similarly, Micheál got a referral straight to his local rural hospital from his GP, where he got a swift diagnosis.

Margaret and David, a married couple originally from a different European country and living in a rural area, were referred straight away by their GP to a local rural hospital after they together expressed worry about Margaret's symptoms. There, the treatment they received left them feeling unhappy and unsatisfied. They met with a doctor and Margaret had scans and tests done, however the doctor's manner led Margaret to exclaim early and unprompted in the interview, "*we had a chap in [hospital] and I didn't like him at all*". Later on, the following exchange explains their experience:

D: I think, to be fair he seemed to be under a hell of a lot of pressure like...

M: and he seemed to be running about

D: he seemed to be running about, he'd get up and run out of the room to go see somebody else

M: and we were just left there

I: oh really

M: yes, no, you know, I'm sorry you know there's a problem can you come another day, and you were down somewhere else, in another room because you weren't in there, and I were left on my own, I did not know what were happening

I: are you serious. And he just let you sit in there?

M: yes, and then he just came in didn't he and said you can go

I: really!

D: well they did a scan like and that, they did the scan

M: probably, but I mean he never said anything about it

D: no, they had to wait for the results and we got the results then

I: and did they bring you back to kind of explain the results of the scan or?

D: no, we went to [Memory Clinic] then you see, he referred us to [Memory Clinic]

As for nearly all of the participants, the memory clinic was where Margaret and David got to meet an appropriate doctor and got their diagnosis, however the experience of the preceding interactions with the healthcare system was often shaped by their interaction with the 'middle stop' between the GP and the memory clinic.

Noírin, a married woman in a rural area, mentioned to her cardiologist that she had nearly missed her appointment because she was struggling to remember things. Having had a fall resulting in a brain injury a few years previously, Noírin had discussed symptoms she was experiencing with her neurologist, and dementia had been mentioned, but nothing came of it. This time, the cardiologist took her complaint seriously and referred her on to a geriatrician, where she eventually got her diagnosis of early onset Alzheimer's Disease. This process was made easier by the fact that the 'middle stop' doctor was proactive and mindful of Noírin's complaints, unlike in Margaret's case, where the 'middle' doctor did not engage with them at all.

Similarly to Noírin, Orlaith, a separated mother of two in a rural area, was with her diabetes doctor and mentioned that she was not feeling well in herself, with her memory "*shot to pieces*". She was experiencing a lot of pressure in her personal life at the time, and the consultant suggested that in addition to the scheduled diabetes check-up they do a number of tests and a brain scan. The scan came back clear, much to Orlaith's relief:

O: ...so in my mind the brain scan would show up plaques, or tangles, and then we would know well it is AD, and if nothing showed up, in my logic head, then it was just memory, and it was something I needed to work on and accept that this is a weakness that I have and I need to cut my cloth accordingly, so the, the scan came back and they said there was nothing on it...so I was fine, I was relieved, I was delighted.

Nevertheless, she still was not feeling well and eventually went to her GP, who knew her very well from dealing with her family and her son's medical problems over the years. Rather than trying to explain away the tiredness and frustration Orlaith felt with all the pressure she was experiencing, the GP took her complaints seriously straight away:

O: He kind of said ok, I don't need to question you, we'll just do the little test we do here, so he did the test and I failed miserably [laughs], miserably, and he says oh Orlaith I think we better, are you ready for this, and I said I am, so therein started then an assessment up in the Memory Clinic.

Again, like a number of the participants, Orlaith's experience of the disclosure of her diagnosis was not a good experience, however up until then her pathway to diagnosis had been fairly clear and straight. Orlaith's GP was fast to recognise that a more specialised investigation was needed, and despite living in a rural provincial area, Orlaith was still quite close geographically to a Memory Clinic which simplified the referral for her. However, her diagnostic journey from this stage onwards was to worsen, as her disclosure experience and its aftermath were not handled well. This was the case for a number of participants; while not all had bad experiences, it is important to note and acknowledge the damaging effect a poorly handled disclosure of an illness like dementia can have on a person, and on the person's ability to come to terms with the diagnosis.

4.4 Disclosure and aftermath

The pathway to diagnosis was quite varied among the participants, as some followed a clear line whereas others were waiting for a long time and were pushed between post and pillar during that time. However, receiving the diagnosis provided direction; once the diagnosis was made and the word was out, the person's life changed and would remain changed. The actual disclosure process was varied, and ranged from very abrupt to clear and supportive. The variation suggests that this is something which doctors are either not used to doing, or do not really follow up on due to the perceived lack of therapeutic help they can give the patients.

In the interest of brevity, unfortunately not all experiences can be discussed in detail. However, I have chosen to analyse in detail five participant's experiences. Niamh, and Tadgh were chosen because their disclosure experiences, while not catastrophic, were still chaotic, unclear and left them to figure out many things on their own – something which it is very doubtful they would have experienced if they had any other illness than dementia. Orlaith, and Seamus and Bláthnaid's experiences, while shocking in the unsympathetic and blunt disclosure, are not uncommon and both of these participants really conveyed how the harsh disclosure and the confused, disordered and disjointed initial care they received, affected them in a damaging and negative way. Similarly, Nóirín describes in a clear and compelling way how the period after diagnosis was made more difficult than it had to be due to a lack of support services.

Niamh had a clear path to diagnosis, in that her GP, on the suggestion of her sister-in-law, referred her straight to the correct doctor at her local small urban hospital, who was able to give her a diagnosis. Nevertheless, the disclosure process that she describes is very abrupt.

N: ...I went to X in, here in [small urban town], and, and he did a battery of his tests and that kind of thing, and some of it was up [inaudible] even you know all the checks and that kind of thing, and then you know he's quite an abrupt guy you know, he sort of just when all the tests were kind of done he said, he said that you have Alzheimer's now and really you have to go and live your life, bye! More or less, that was it.

Niamh was not given any information about AD, and while it was unclear if she still attends the specialist as she was not sure herself, she did stress that she goes to her GP if she has any issues. She was also involved in a clinical trial which a friend who is a nurse got her involved in. She was full of praise for the staff and doctor in the clinical trial, who were based in a Memory Clinic in a major urban centre, and Niamh seemed to have got information and support from them. She also did not seem to mind her consultant's disclosure behaviour too much:

N: Now he is an abrupt guy, and I suppose he is a very busy guy as well you know, so, I didn't mind that as much, too much, I mean we had an inkling anyway, so.

Niamh could not remember how she reacted to the diagnosis, but does remember that she "...knew there was something really, you know, not right." She also took the diagnosis in her stride, and instead looked to the future. Her attitude and reaction to her illness is discussed in more detail in the third Findings chapter, however it was both remarkable and fairly unusual,

in that she very quickly seemed to accept the diagnosis and really made the most of it in terms of how it affected her life.

N: I was kind of relieved that it was over, you know, that everything like that was over and I could go forward myself, you know.

Seamus and Bláthnaid had a particularly difficult disclosure experience, and their experience gives a good insight into how a poorly handled diagnostic disclosure can affect the person and their family. Seamus and his partner Bláthnaid lived at the outskirts of a major urban centre. Seamus had experienced two brain seizures and been taken to hospital at the time of diagnosis. As he was very sick when he got his diagnosis, he was not aware of many of the events and experiences that took place around that time, and Bláthnaid was the person left dealing with all of them. They also had a difficult and complicated home situation, which meant that they were not getting any family support. In essence, this meant that Bláthnaid was left dealing with Seamus' illness, the immediate practical issues around it, and the ramifications of it on their future and their life together, virtually alone. When she eventually was able to access support groups, it was after going through a very difficult time and also finding it very difficult to even find information about groups, especially relating to YOD.

After his initial hospital stay following his brain seizures, Seamus was taken into another hospital for further tests a few weeks later. The first, smaller hospital rang Bláthnaid, and told her over the phone at work that Seamus had cognitive impairment:

B: so a doctor in [hospital name] actually rang me and said over the phone at work that it was...

I: cognitive impairment, just like that

B: yes, just like that, oh yes, so I had to say to her, ok what's cognitive impairment...and she said it is early onset dementia, so of course I nearly fell off the floor.

The blunt delivery of diagnosis over the phone continued when the results from the larger hospital came in:

B: and in [hospital name], the very same thing happened, different doctor, different hospital, both young women doctors we ended up with, that's nothing to do with it, he was in [hospital] for a week, they did every test under the sun, and again, a doctor rings me, young doctor, now this time I knew what cognitive impairment was obviously because the first doctor had said it, so the second doctor said it is cognitive

impairment, and I wasn't given a fact sheet, an information sheet, I was given no information and nothing about anything, I was left floundering, and that's part of the reason I had such an awful meltdown at that time because I just thought what am I going to do where am I going to go?

I: so it was just, right cognitive impairment now you have a good day goodbye click

B: yes, it actually was something very much along the lines like that

S: yes

B: and to the second doctor I said, and are there any support systems or anything there, she said well there is a very good website, Alzheimer, well I knew, there is a website for anything so she wasn't telling me anything I didn't know there, but I got zero information about support groups, help, nurse, social worker, community care, nothing, I got nothing, so I went into a whirl of total panic.

The suddenness of the diagnosis and the lack of any information or even a face-to-face meeting where reactions could be gauged and questions asked affected Bláthnaid deeply.

B: ...the first doctor said to me about the EPA, you'll need to get an EPA done, on the phone again, real casual, and I said EPA, what's an EPA and where do I get one I said, she said it is an enduring power of attorney, ok, and where will I get one of those and what is it, like, what! So she just said on the phone you need to go to a solicitor, that was it, they were my two diagnosis, over the phone, as casual as be damn, and both times I was expecting each doctor to tell me, in the first hospital to come in and discuss the seizures and why would a healthy man get seizures, and second time I thought they were bringing me in to discuss the, or ringing me to tell me to come in to have a discussion about of the results of all the tests that they had done in [hospital], so that was how I got to hear about it.

Adding complexity to their situation was that they were involved in an ownership twist with Seamus' family regarding their family home. This already stressful situation was exacerbated by the diagnosis of dementia, and the non-supportive way in which it was handled pushed Bláthnaid to the edge.

B: ...I was in a really bad place, and, then the awful complication we have with our in-laws here so that's another issue, another complexity, so because of both of those I was in an awful state, and, I rang everywhere, I rang, I got on the website, I rang, I was

like a demented I don't know what ringing around trying to find people that would tell me who or what and why, what do I do, where do I go, what do I do, dum dum dum, I was in an awful state for ages...

Left alone to deal with Seamus' diagnosis and the situation with the in-laws, and with no follow-up from either hospital or no indication of where help could be sought, Bláthnaid tried to reach out to anything and anybody she could think of:

B: I was on the web, I was on the phone like a demented lunatic and I remember ringing loads of numbers and somewhere in that haze of calls that I was making over the weeks, trying to speak to anybody, you get answering machines all over the place and [Memory Clinic social worker] rang me back from one of them, I had no idea, and I had to ask him two or three times over the phone, who are you again, and where, I was so gone, you know, he rang me at work and I said this is who I am, this is what I have just been told, I have no idea, so, he rang me and I was in a distraught state because at that point in time I couldn't stop crying, I was just crying, every day all day, I was just so distraught ... I just thought this can't be happening, and then given the complexities of our situation here I knew it would be multiplied by a hundred...and all I did was cry when I was trying to explain to him about the situation here, in-laws, dum dum dum dum, to this day I don't even know if I made sense...

The Memory Clinic were able to point Bláthnaid in the direction of local dementia support groups, and she attended everything she could find in order to learn more and find out how to access support.

B: I went myself and I booked a course, really, really good, brilliant course for a week, secretly, took a week's holiday off work, and I did a course in, which is part of the whole thing about saving my life at the time, in [local hospice] they have a very good education and research department, and they were running a week-long course, 500 quid it cost me, for one week, on Alzheimer and communication and what you do, what you don't do, what it is about, who what where and why, and I cried for the five days during the course, for the five days, from the minute the course started and it ended, there was a brilliant tutor there... fantastic, and that was the beginning of me maybe getting my bearings whatever, whatever, it was a very difficult.

At the time of the interview, Bláthnaid regularly attended a local dementia support group, and Seamus was involved in a research project run by a local university, which also provided good

support. Despite not having any younger persons with dementia in it, the local dementia support group was very important for Bláthnaid:

B: I go to them still, religiously, once a month...I think I am the only person in the entire group that goes religiously, because I am so afraid not to go... and the woman that runs it, well not runs it but she said you know Bláthnaid, she said someday I hope that you will be ok enough not to need to come every month.

Bláthnaid had to find out everything for herself about the disease, and feels that the hospital's lack of support contributed to her difficulties:

B: ...to this day, [hospital] hasn't handed me a sheet of paper, to say this is Alzheimer's, what it is, what it isn't, there are support groups, Alzheimer's Cafes, there's this, there's that...I was wiped out though, I can tell you that now, the damage it did to me was horrendous, on an individual level...it was like a hammer on the head into the face, that's what it was really like, it was like someone got a hammer right into my face, and that's what it did, it just broke me completely...

Orlaith was referred straight by her GP to her local Memory Clinic, where she went for an assessment. However, her disclosure of diagnosis and the interaction with doctors afterwards was a very confusing and chaotic experience. She was assessed by a team at her local Memory Clinic in a rural town, and a few months later was called back. Not knowing what to expect from the meeting, she was none the wiser afterwards:

O: ...so they started talking and really what I got was medical babble, so we see this and they kept saying cognitive impairment, and I was kind of going well I kind of know a bit about cognitive impairment and it is only, and this went on and I asked questions, what can I do, you know, what's my recipe, or what's the plan, and they were kind of saying well, you know, we'll watch it and it might stay where it is and you know, I thought I asked all the appropriate questions from my care and my care plan, so I came out still rattled, but no words.

Having asked about medication and being told she did not need it, Orlaith was on her way to her car when a nurse who had been part of the original assessment team came running out after her.

O: ...she says I'm so, so sorry I wasn't there with you to hear that she said, I was called away I had planned to be there, and as she was saying it, I was going why would she need to be with me, unless I heard something devastating, and I just looked her

straight in the face and I said to her, are you telling me I have Alzheimer's, and she said yes, did they not say that to you? So I'm in this car park, like, so, I just burst into tears, I just was devastated...

As she was supposed to meet her son an hour later, Orlaith had to pull herself together and deal with all her emotions later. The doctor rang her back the same day to say that the group had discussed and re-evaluated their decision on medication, and she took the medication for about three weeks but had to stop because of severe side effects. The doctor suggested a different medication, but then went on holidays and his replacement did not want to give her the medication; she was sent to her local hospital instead of the Memory Clinic to get the medication. The doctor that saw her in the local hospital did not know anything about the medication but instead thought she was there for an assessment; when the consultant came in and looked at her file, he realised it was the local hospital file only and not the Memory Clinic one, which it should have been, and told her he was not comfortable prescribing such medication. So, in the end she had to wait until the original doctor was back from his holidays, adding greatly to her already strong sense of confusion about everything. Orlaith was also scheduled to meet a psychiatrist, who insisted she take medication for depression even though she did not feel depressed. She then looked at Orlaith's medication and said that medication she was taking for a leaking bladder issue was counteracting the medication she had been given for the Alzheimer's. At this stage, she was sick of all the confusion:

O: I'm fairly intelligent and articulate and can fight my own battle but what about somebody who is, a little elderly couple who have never dealt much with doctors... so I went in to them and again, I turned up on my own, I'm pretty much able to answer for myself, and I came out and I thought if I never see a doctor again it would be fine by me... and so I'm telling you what's going on in my life, I'm living on my own, I'm a lone parent with two guys, I have one guy who has psychological issues I'm trying to keep him on an even keel and work with him, life is tough, but I feel well, and I just came out, I felt like I was a little puppy dog that they patronised and patted on my head, and I felt you know what you've actually done me no good, at the tail of end...

Fed up, feeling patronised and not getting anywhere, Orlaith went to her GP, whom she had known for many years and trusted completely, to figure out what to do about the medicines:

O:...I said to him, I have a bit of a puzzle for you, so I explained, I said I'm actually at the stage wondering if there is something more wrong with my brain that I'm not hearing these people right... so we literally sat and chatted and figured out what I

needed in my life... he said well I'll check in with you every month or two months, if you notice anything strange, anything weird, anything at all, come back to me, and he said I have to say sorry Orlaith that you are going through something devastating and this is the support and the help you are getting.

The nurse from the Memory Clinic had offered to meet with Orlaith again, and it was the first and only time she got clear information apart from her GP.

O: ...that nurse who ran out after me said to me please come back in two weeks and we'll have a cup of tea and we'll sit down and I'll answer any questions you have, and sat down with her and I said...can you please tell me do I have AD and she said you do, yet they just seemed to be backtracking and not willing to put a name on it, why, I don't know, I did ask somebody, I can't remember who I was talking to in the Alzheimer's, and they said there would be not necessarily a conflict but it seems to be a very regular occurrence that people are not being said straight up this is what's happening, this is what you need to do, this is the help you can get, or the help you can access, it just seems to be, and then I seem to have confounded them all because I just go in and I'm very organised and I tell them and all the rest of it, but that's who I am, it doesn't mean I don't struggle hugely with life.

Orlaith was the only participant who got clarity from her GP, as opposed to the specialists or the Memory Clinic. In her case, the Memory Clinic was unhelpful and apart from the nurse who went out of her way to contact and help Orlaith, outright unsupportive and patronising. Orlaith's bad experience with the Memory Clinic and good experience with her GP was the opposite of what most participants had experienced, however in her case her GP listened to her, took her concerns and needs seriously, and involved her in planning for the future and how to structure her care. The fact that she was on such good terms with her GP obviously helped in this case, however her experience shows that with the right knowledge and commitment, GPs can be a great help and source of support.

Tadgh's experience with the private scans and geriatrician before he got referred on to the Memory Clinic highlights the lack of a clear pathway for younger people with dementia. Neither the GP nor the geriatrician quite knew how to care best for Tadgh, nevertheless the geriatrician's referral to the Memory Clinic finally led Tadgh and Caoimhe to the right place:

C: I didn't know what other route to go down to be honest, and because we had the MRI privately, maybe that's why the GP referred us to the same guy, I don't know, like I

honestly, I'd never heard of [the Memory Clinic] having, well of course I didn't know what route to take, and I knew a geriatrician wouldn't necessarily be appropriate, but that's what the GP referred, said, you know.

They also had issues with the medication that the geriatrician had prescribed for Tadgh. The geriatrician put him on Aricept, a medication for AD, despite Tadgh's diagnosis of FTD. Tadgh experienced strong side effects from the medication, and when Caoimhe rang the geriatrician for advice, he told her *"you [are] probably better off to discontinue it because it is really no good for FTD anyway, as such, it is more for memory, you know..."* This raises the question of why he put Tadgh on the medication to begin with, if it had no relevance for FTD; this ad-hoc approach to the specific subtype of dementia is quite shocking.

The family GP, whom Caoimhe liked very much but describes as *"old school, doesn't even have a secretary"*, was startled at the result of the MRI and while supportive, not very much help:

C: He hadn't ever heard of it actually, he'd heard of AD but he couldn't believe and, to this day he's still, ah it's unbelievable like, given his age and, he had actually never heard of FTD prior... he'll always say and how is Tadgh, I'm still shocked, you know, almost like he is still, he almost can't believe it....

Currently, Tadgh visits a neurologist in the nearby city, which he sees approximately every 5-6 months. Caoimhe describes their meetings as: *"to be honest, he doesn't do very much, again because he has very few answers, he will kind of ask questions, you know, and I answer"*. They are still in contact with the Memory Clinic, despite the geographical distance:

C: ...but I still call [name] every now and again, because, and they did say the day we left [major urban city], like you are finished with us because you live in [name of town] and you know, but don't ever feel you can never phone us up if you have a problem or, so yes, I felt extremely comfortable with him, and they knew what they were doing...

On a personal level, the diagnostic process was difficult mainly for Caoimhe, as Tadgh had limited interest into what was happening. When the GP told her over the phone that they had found a significant atrophy in Tadgh's brain, it did not really register with him:

C: ...when I told Tadgh that morning after hanging up the phone, I was actually making a dessert and he was kind of putting the fruit on it, when the phone, I was putting the fruit on it when the phone rang, and when I went to answer the phone he said do you want me to continue, so I said ok so when I came off the phone of course I was, tears and, asked if he wanted to sit down he said why I said I have something to tell you and

told him in as plain English as I could, you know you have a form of dementia, it's not, it doesn't look like Alzheimer's but it something along those lines, ok...[he then replied] do you want me to put more strawberries on this, and it has never really been any different.

Noirín's disclosure experience was not as shocking and blunt as for example Seamus and Bláthnaid, but nevertheless the aftermath was similarly difficult. Her diagnosis of Alzheimer's Disease was compounded by Noirín having to leave work early and resign from her many community involvements which had been part of her life for decades. At this stage, she did not know what to do or where to turn, and like Seamus was essentially left to her own devices. She describes this period as a black hole:

N: ...it was absolutely a bereavement for 10 months, because, there was nowhere to go, there was nobody to talk to, you went to your doctor your doctor you know told you all he could tell you, and there is nobody and that's it, and you have to work out that grief because it is absolutely the blackest place you could ever go to, and you think about the wonderful life you had, all the, the travelling, the excitement, the jobs, the, your family life, your fullness, your happiness, and then you find yourself in a black hole...

Encouraged by her husband and her doctor, Noirín tried to engage with what services existed in her area. These consisted of day centres run by the ASI, and having been involved in the disability sector for many years, Noirín knew what to expect. She decided to visit one of the centres, but chose one in a neighbouring county as she was familiar already with the one in her own county:

N: ...so I went and decided then ok I will go to the ASI, one day here I just put on my jacket and just thought I was going to drive up and I drove to [neighbouring county] which is about, I knew about the one in [home county] and I just absolutely cried my eyes out because I thought I couldn't go down there, they are all in their 80s and 90s, you know, they are just, you know, so senile, but I just couldn't see myself, what was I going to do, I've been, working in disability everything about day centres and all the rest, and, so I managed services in disability so I knew exactly what was facing me...

Despite this, she went to the centre in the neighbouring county to see what was there and if there was any support she could get. Once there, she was greeted by a very friendly nurse, however the rest of the visit was not a positive experience:

N: ...I went in to that centre and they were having some kind of a service and it was a cold day in the beginning of November and I absolutely thought I'd never get out of the place because only for the nurse was so nice to me I don't think I don't know how I would have survived because it was just like, is this it, is this where I'm going to be, you know... I came out in the car and I cried and I cried and I cried...

The lack of services that Noírin experienced was not restricted to meeting other people with similar issues. Her doctor had mentioned that she would need to get her driving assessed, however when she tried to find information about this, she found nothing. Drawing on her contacts from working in the disability sector, she tried to contact occupational therapists and other professionals who, despite their best efforts, could not help her in any way. In the end, she was able to get her driving assessed through personal contacts within a specific disability charity, which was in no way connected to dementia services.

4.5 Discussion and concluding thoughts

This first Findings chapter introduced the participants of the study, and described their pathway to a diagnosis, from the first symptoms, to the search for the correct diagnosis, the disclosure experience, and the period after the disclosure process. The interaction between the participant and the health care system is described through their experiences, which varied from upsetting but appropriate to wildly inadequate and causing harm.

As has previously been mentioned, getting a diagnosis of dementia is a complex process, and for the participants in this study it generally included multiple visits to their GP, referrals to specialists/Memory Clinics, waiting time to see a specialist, and a number of tests before the diagnosis was confirmed. The variation of symptoms that the participants experienced are quite typical of the wide ranges of YOD. Tadgh experienced personality change and apathy, typical of FTD; Niamh could not count anymore, and both she, Fintan and Fionn were struggling with sequential tasks.

Initially, most participants did not suspect they had dementia; the only exception was Fintan, who recognised his symptoms from his father's behaviour with YOD. However, the majority of participants were puzzled by what was causing their difficulties. Based on his previous experience with depression, Fionn and Maeve both thought Fionn's symptoms may be related to mental health; likewise, Aisling at first did not think of dementia but rather thought stress was the cause of Sean's behaviour. Caoimhe described her concerns vividly, stating that she was hoping and praying that it was 'only depression'. Here, she is fearful of something worse,

perhaps fatal like a brain tumour; or something even more disturbing, like dementia. The sense of foreboding is powerful and illustrates the strong fear of something as of yet unknown.

One of the main findings from this chapter was the extent to which the pathways to diagnosis were many, varied, unclear, uncharted, and confusing. Many participants saw at least one specialist after their GP who was not able to diagnose or help them; these specialists seemed to not quite know what they were dealing with and could not diagnose or help, and many participants found the experience frustrating and time consuming. For example spending time with a psychiatrist and trying to find the correct balance of medication for depression meant Fionn was receiving unrelated treatment, and further delayed diagnosis.

Many GPs are loath to even think about dementia as a possibility, as it is considered one of the worst diagnoses to have to give to a patient, and can avoid investigating the possibility for a long time (Moore & Cahill, 2013). Both Fionn and Maeve, and Tadhg and Caoimhe, describe having to 'push' their GP for a further explanation or investigation into symptoms, with Caoimhe going as far as to make up symptoms that she knew would make the GP react and give Tadhg a referral. Many GPs do not consider dementia as a possibility because of the age of the person (Chaston, 2011), and this, in combination with the reluctance to investigate and diagnose dementia, contributes to barriers to diagnosis. Moreover, the ease with which a person can access diagnostic services is very dependent on where in Ireland that person lives. For example, most Memory Clinics are located in Dublin, meaning that a person in other parts of the country will either have to travel to Dublin or rely on hospital services locally, which may not have the same expertise and degree of specialisation when it comes to diagnosing dementia. However, geography is not always a culprit as can be seen in the example of Fionn, who lived very close to two major hospitals but still waited 18 months for a diagnosis; or Orlaith, who lived close to a Memory Clinic but was still not given her diagnosis in an appropriate way.

This chapter reveals that for most participants, the process of diagnosing their YOD was confusing, upsetting, and ad-hoc. While it is not likely that a diagnosis of a terminal degenerative illness is ever going to be a pleasant experience, the difficulties and confusing nature of trying to get diagnosed added to the distress of the process, in some cases devastatingly so. The data clearly shows the distress caused by the process, even if there were some examples of where having services in place helped support the person with YOD and the family, such as the social worker present at Sean's disclosure meeting. Birt and colleagues

argue that the period before diagnosis is an unsettling and ambiguous experience, where the person nearly disappears due to the lack of definition of their symptoms (Birt et al., 2017); this invisibility, in the case of the participants in the study, contributed to the complexity of the pathways the participants had to negotiate in order to get a diagnosis.

While getting a diagnosis was a hugely important step, the findings of this study show that receiving a diagnosis was not the end of the confusion for the participants. The disclosure process was often not appropriate, with evasion and avoidance instead of clear speaking and unambiguity being employed by the medical professionals. In addition to this, the lack of immediate supports, whether practical or mental, were glaring in their absence and the overall lack of a support services very soon became apparent for most participants.

Two of the very bad experiences of disclosure, those of Orlatih, and Seamus and Bláthnaid, revealed an alarming disconnect between the medical professional and the person with YOD, and a disregard for the effect that the disclosure process would have on the person. Bláthnaid describing how she felt that she had been hit with a hammer, and that the experience broke her, was a powerful narrative of the effect such poor handling of a situation by in this case not one, but two, different medical professionals can have. Orlaith's experience of being told her diagnosis nearly by accident in a car park after being patronised by a room full of medical professionals, and her subsequent bizarre and roundabout experience of trying to access medication, were both astounding in their complete disregard for the person at the centre.

Some participants had a good experience of the disclosure, such as for example Sean and Aisling, where the doctor told them the type of dementia Sean had, made sure that they had opportunities to ask questions, and, crucially, that there was professional support available, in the shape of an experienced and knowledgeable social worker. The relative ease with which this was done raises the question why health care professionals are not better at giving a diagnosis, especially those who are familiar with YOD. In relation to LOD, many GPs do not tell their patients that they have dementia, but instead use vague language or speak about undefined 'memory issues'; this is a glaring difference from a general disclosure rate for terminal cancer of 95% (Cahill et al., 2006; Moore & Cahill, 2013; Ólafsdóttir et al., 2000). It is very difficult to not ascribe the reluctance to even speak the word dementia, and the nihilism regarding the quality of life and the prospects for the person with dementia, to the heavy stigma surrounding it.

The feelings of bereavement, grief, of having no one to talk to and of being in a 'black hole' that Noírín spoke about powerfully illustrate the weight of the diagnosis, and also the way in

which a person diagnosed with YOD is left on their own to deal with the consequences: *“there was nowhere to go, there was nobody to talk to, you went to your doctor your doctor you know told you all he could tell you, and there is nobody and that's it”*. This complete lack of supports, and the stigma which runs like an undercurrent through most of the narratives, are the subject of the next Findings chapter, which looks at the implications and experiences of life with YOD.

CHAPTER FIVE – FINDINGS AND DISCUSSION II: EXPERIENCES OF LIVING WITH YOUNG ONSET DEMENTIA

5.1 Introduction

The often long and unwieldy process of getting a diagnosis for their YOD was in a way only the start of the participants' issues with accessing services in relation to their illness. Much like the diagnostic pathway, finding services that were suitable was a challenge for many participants, with so few services available specifically for those with YOD. Also, with a diagnosis of YOD, the participants were now becoming familiar with the stigma that surrounds dementia, and the ways in which YOD brought with it specific challenges. These two topics are the subject of this second Findings chapter.

5.2 Stigma

At the heart of living with dementia is the stigma of the illness, and this is no different for young people with dementia. The stigma of dementia tends to be double for older persons with dementia, including ageism and mental health stigma. While persons with young onset dementia might not in all cases face the ageism stigma, they still face the mental illness one, as well as the nihilism and lack of treatment that healthcare professionals such as GPs tend to feel about the issue. Moreover, as dementia is associated with ageing, being young with dementia is non-normative and stigmatised (Tolhurst et al., 2014).

Stigma was evident in the previous Findings chapter, where many participants were sent from doctor to doctor as no doctor quite knew what was wrong, or alternatively were given medication even though it was for the wrong illness. In this section, we will look at the various instances when the participants talk about stigma, where they experience it, or how they deal with it.

When Noírin first began telling people that she had been diagnosed with dementia, her friends and colleagues were upset and understanding, but also often rebuffed what she said – insisting that surely she did not have dementia, but rather that her problems were being caused by a long list of other things. Knowing full well that her issues were not caused by any of the suggestions she was getting, Noírin was frustrated by their suggestions.

N: ...I started to tell people I rang some friends of mine... and they were so upset, you know, they really, really, I mean they were tearful, they were so upset that I just, you know, it was an emotional moment for all of us, so then I, after that then I started to

tell people...and slowly but surely began to tell my old employees and colleagues at work and, I got that out of the way and of course you had all, everyone was the same practically, 'oh for God's sake take no notice', 'it is your age, you are under too much pressure, you have too many things going on', but at this stage I had given up everything, so you know, it wasn't any of the above...

The unwillingness to face and accept Noírin's diagnosis from her colleagues is echoed in the stories of some of the other participants of the study, and shows the fundamental discomfort of the diagnosis – a person who is told of the diagnosis does not accept it, as they do not know how to deal with it and instead just denies that it is there. This 'uncomfortable' reality of dementia then leads to people keeping a distance and not engaging with the person with dementia, as Noírin explained.

N: ...I often say that in my speeches, if I did [have cancer instead of dementia] it would be different, if I did I wouldn't have the isolation, you lose a lot of friends with this illness, you lose an awful lot of friends with this illness, because people don't know what to say to you, they don't know how to talk to you, they don't know, they'd rather walk the, I've had people walk the other side of the street, because they don't know what to say, because we don't talk about the illness, we're all mad, mentally ill, put us away, that's the old thoughts of it in rural Ireland, in Ireland full stop, and it's not just Ireland in all fairness, in other countries as well, but it's that whole myth around the illness, how can you live, how could you have that, 'I don't believe you have it', you know, that sort of...

Noírin's activism is a direct head-on challenge to the stigma and silence surrounding dementia, and she is nearly unstoppable in her dedication and her determination to change how dementia is perceived and how people with dementia are treated.

N: How I look at it now is by me going out there and fighting the fight every single day by making myself visible in my community, by, whether it is by driving or walking or shopping or whatever, and of course I forget things and of course I can't find things but that's alright, they all know me now, so, in the store, of course mind you they move it around quite a bit so [both laugh] but I do think that that's helping, that's helping people's understanding and getting rid of stigma, but I also think that the more awareness we bring to the table the more awareness we bring to the public...

Contrary to most, Niamh had not noticed any issues in terms of stigma, which reflected the sunny outlook she had on her life, and how she felt that her quality of life had improved since she got YOD. However, in one revealing paragraph, she described how her illness was a source of gossip in her town:

I: and you've been able to, you feel completely comfortable about being open about the diagnosis

N: yes, yes, now somebody, when I first kind of came, well not came out as such but, the very, very, early days somebody picked up, because I have friends who are nurses but I don't think it was them, somebody came, somebody picked it up and found out that I had AD practically nearly before I did [laughs] which was kind of funny, but this road is just, every, from say from the [X road] all the way up around here and beyond, you know everybody knows everybody, so

I: yes, they kind of know each other's business

N: yes, so it flew around like God knows what, you know

The fact that the whole area was talking about her illness, and the fact that someone with knowledge of her private medical information had been talking, did not seem to bother Niamh. Throughout the interview, she was very focused on the good sides of her illness and how important positivity was; she nevertheless was well able to describe when she was upset about something, for example how she was treated in work before her diagnosis. So it seemed like the leaking of her diagnosis and being 'the talk of the town' did not bother Niamh, as she steadfastly focused only on the positive. Also, her experiences of support from her community were overall good, which may have contributed to her not attaching any malice to the gossip.

Orlaith spoke eloquently and at length about stigma. Outspoken in both local and national media about her condition, she was well known in her rural area and described people approaching her asking about dementia. However, she also had people avoid her as they did not know how to deal with her:

O: I actually had, and the reaction is just, like I can see how people would get upset and hurt, I've had one friend, who wouldn't hug me anymore, you would have always got a hug when you met them, and I want to say to her it's not catching! ...I've had a lady who I would know quite well from where we used to live and three times in Tesco, and Tesco in [town] is huge, three different times she came up an aisle, spotted me, and went the other way, now, I wasn't really in a position at that stage to go and say you

know hi [name], I didn't change, I don't need to talk about it, you don't need to be uncomfortable, I don't need to say anything, it's just, you know, this is the way it is [pauses to give out to dog] you know to say to her like, now I would be able to go and say because I feel I don't want anybody to be uncomfortable or have the fear

Orlaith has learnt from living with dementia that doing things can take longer, or that it is easier to get flustered, and has begun stating outright that she needs more time because of her dementia:

O: ...if something is kind of pressing down on you immediately, panic can set in, and so that panic of course upscuttles everything then, you're 10 times worse you know, so I'm learning now to be able to say 'would you like to go ahead of me' or 'excuse me I have dementia I need to take a moment' or 'can I hand you my diary' and those kind of things...

Being able to say straight out to someone that they did not have anything to fear was not something Orlaith was always able to do – rather, it has come from being active in raising awareness of dementia, and speaking out. Nevertheless, the misconceptions about dementia and the reluctance to accept the illness is very strong among people, even in Orlaith's own family.

O: ...one of my own brothers, when I said it to him [he replied] 'ah you'll get over that', and I'm kind of going ok, alright, like it is their perception and their fear, you know...

Her brother in this case would not even acknowledge that she had an irreversible illness, and did not want to engage in it or take it onboard. Orlaith was aware that most people would not have her experience of being able to deal with situations through being used to speaking out. She describes a particularly sad case of a lady who described being left out completely:

O: ...and this big huge area, you know of actually naming it [dementia], and saying it...within three miles of here there is another lady diagnosed since last March, and she's devastated, she's friends turning away from her, she has people she worked with walking the other way not having conversations with her she is being treated so, and she's really hurting at the moment and she's hurting twice as much because of how these people are treating her, and saying no we'll have [name of town] will have dementia-friendly by the end of the year, we need to get the word out, we need to be screaming and shouting, we don't change just because we get labelled, and when we most need people is when we really don't need you to turn and give us the cold

shoulder ... but I can see how this other lady is just devastated, she wouldn't have, she would be a very simple soul and that's not derogatory, a very simple soul, very honest, salt of the earth and can't now figure out why these people are, what did she do to them, what, how is she, and I just think when you so need your friends...

It is very important for Orlaith to show that it is possible to live well with dementia, and she uses her awareness-raising not only to make life easier for those with dementia, but chiefly to break the stigma and challenge the narrative of dementia.

.

Another participant who was very open about his diagnosis and also was active in raising awareness was Fintan. Fintan was diagnosed early, and had cared for his father who also had dementia. He used both the knowledge of the illness from his father's experience, and having it himself, to speak about it to combat stigma and ignorance. He described his reasoning behind speaking out about having dementia:

F: ...I think there is huge discomfort, and I find, people are you know, quite a number of people are in some strange way they are shocked that I am prepared to talk about it, it's like I should be keeping it a secret, and I can feel them sort of looking at me saying you shouldn't be telling people this, you know, and I say hang on that's stupid, because it just creates this complete barrier, you know, you either don't have it and it is ok or you have it and it is a disaster.

The stigma surrounding dementia is harmful on all levels – it stigmatises the person, and, as Fintan explains, also leads to unnecessary worry and panic on diagnosis, something which he experienced himself despite his experience of his father's illness:

F: on receiving the diagnosis my immediate instinct was to slightly overreact and kind of start changing everything, and this is I think particularly pertinent for people who might get an early onset diagnosis, combined with the, you know the terror that surrounds the condition, it could incline people to kind of panic into an immediate you know, complete overturning of their life, and in fact that is not necessary, that's not necessary, it is inappropriate actually, so that's another part that I feel would be useful to get talked about...

The upheaval which follows a diagnosis is, in other words, not appropriate and not in proportion with the immediate future, especially for early diagnosis. The illness trajectory is different for each person, is very individual, and the stereotypical image of someone living

with dementia as old, decrepit, and mentally completely incapacitated is not correct for a large part of the course of YOD or the population with YOD. Fintan puts this stereotype, and the aversion people have to even speaking about dementia, down to fear:

F: there is actually no reason, no need to be, to treat this as some sort of pariah condition, a taboo, it is just, it's a, you know an acquired progressive disability and like any other acquired progressive disability its early stages can be extraordinarily mild, you know...but I do think it is motivated by fear, it is fear, it is just people 'oh Jesus', and embarrassment, the fear of being embarrassed, and you know causing social, you know social disease really, awkwardness...I think what motivates that extremity is actually just discomfort, people just don't feel they are capable of handling it, and they do kind of feel if you say yes, you know I have been diagnosed with early onset dementia, the immediate response is oh God this could be really embarrassing, any moment now they'll say something really and I won't know what to say, it is like a terror almost.

Fintan has painted a picture of a stigma that is nearly infectious – the person with YOD, even when trying to combat the stigma and being open about it, is being reduced to their illness as the other person's reaction to the situation is primarily one of fear of the condition, and fear of embarrassment.

For Sean, the stigma of having dementia led to self-censoring and reticent behaviour. Aisling explained that Sean did not want anyone to know about his diagnosis; this decision was based mainly on his worry about not being able to keep up with conversations:

A: he's told me he doesn't want anyone knowing, obviously family members know, just two neighbours that we would be close to now, and I haven't told anyone else

S: mmm

I: ok, so you just feel that you kind of want to keep it private?

S: yes

A: he doesn't want anyone in the community knowing, because I, and I don't feel he's at a stage that people need to know, if it ever did get so progressive that I have to let people know, listen that's what's wrong with him, you know.

Aisling explained that because of this, their social life has been scaled back.

A: ...we were never great pub drinkers, as such, when we had a mortgage and all to pay we sort of only ever had a drink at home, so we sort of lost that social aspect and then just before Sean was diagnosed we picked up with this couple that Sean, your man was his best man, they are only around the corner, now we've gone out for a couple of drinks with them to the pub that we always drank in but I find every time we go up there, there is either somebody bringing up something about the past, or, now Sean would have been well known, [son's name] is mad into the motorbikes, Sean would have been well known about the motorbikes around here when he was only a teenager, everyone knew him, used to fix everyone's bike [Sean laughs] so it's got to the stage now that I think there is a fear with him now that when someone is discussing something that he won't be able to give his tuppence worth, without this happening to him... so there is a bit of a withdrawal, he has, it's only people he's really comfortable with that he'll socialise with

The fear of anyone knowing about his dementia, or figuring out that 'something is wrong' because of his difficulties in keeping up with conversations, have led both Sean and Aisling to restrict themselves, bot socially and in terms of who they can depend on for support in relation to Sean's condition.

In contrast, Fionn was very open with his friends and family about his illness. Maeve and he had reaped great benefit from this through people rallying around to spend time with Fionn, helping out, visiting, making sure he got out of the house during the day when Maeve was at work, and so on. However, even they had balked at telling certain parts of their social circle, as the following exchange shows:

M: I know that there are friends that we haven't told, you know, that you specifically don't want to tell because, you know that, just because, and we do socialise with them and it is difficult

F: yes, yes

M: see I just believe in communication and you know you told [names], friends of ours, and now we can go out and relax and have a meal and you know I'm not overcompensating, or worrying what they are thinking, you know, when we go to that other couple's house

F: no, I wouldn't tell them

M: no, you don't want to tell them, which is fair enough and I understand it and, but then it is difficult, you know, and people have their own ideas of what's up like, you know, but that's their business and there is a bit because you know that that particular person would gossip

F: exactly, that's the only, yes

M: whereas the other friends that we've told, you know that they have your best interest...

Fionn and Maeve had decided to not tell one couple in particular about Fionn's diagnosis as they gossip, and they did not want to be the source of their gossip. However, the exchange between Fionn and Maeve also reveals the relief they both have when they can be open about the diagnosis and not worry about behaving 'properly'. It is interesting that it is Maeve who mentions it, showing that while it is obviously very difficult for the person with dementia to feel that they perhaps cannot follow in the conversation or speak as they used to, there is also heavy pressure on the partner to "overcompensate" for any variations in behaviour, and be on guard constantly.

For Tadgh, stigma also came up un-prompted in the interview. When speaking about how the children are coping with Tadgh's illness, Caoimhe explains that they are struggling, and then says:

C: I know it sounds terrible but I would say give me cancer any day, because it is more known about, there is more, there is no stigma, because, there is with this, I can see people not knowing what to say, very much so.

Living in a very rural setting, Caoimhe felt that she needed to tell people, and as all of Tadgh's family live in the surrounding townland they, together with the local community, help and keep an eye on him. Tadgh's family were not overly pleased with the illness being public knowledge, however Caoimhe had good reason to be open about the diagnosis:

C: it is now, because, simple reason, where we live, as you can see, if Tadgh goes for a walk, not so much now but in the beginning, when he was off work first, there is a loop and it is three miles and he used to do that maybe 6 or 7 times a day, whether, I don't know did he remember doing it the first time but he just, what he did, so I kind of, once all his family knew, I put it out there because, I said that if the day will come that he ever gets lost, or, and I can't lock him in, you know, so, that was my take on it, and like I have gotten a couple of phone calls saying 'it is lashing rain will I bring him home', or,

'I dropped him yesterday I don't know if he told you', you know, so, yes, I don't, I think, the family didn't particularly like that to begin with, no, now if it was something else I mightn't have been so, but to me, because of the nature of the disease and because of his behaviour, I also wanted to explain that if he did something that he wouldn't normally do, you know, because there was one or two things when he stole flowers and, you know, he talks to people he wouldn't normally and, you know.

By taking this open and practical approach, Caoimhe has put her and her immediate family's needs over the opinions of Tadgh's family and with a good outcome, where the small but tight-knit community all know about Tadgh's issues, and can help out in a way that is beneficial both for him and for Caoimhe. Despite her openness and despite the help and support they generally receive, there is still an aversion amongst some people to get too close, and they do not seem to know how to behave in Tadgh's company.

C: I sort of see people, the way they talk, or approach him, or not, you know, because there was one or two now of his, like close friends that, if I ever meet them out and they have a drink, this is very common, 'we'll call back', now when the drink is on board, and then, you never see them, because we have been out a few times locally, and, at the end of the night, because they are all similar to him at the end of the night [all laugh] I swear, if I could bring him to any pub at closing time he'd fit right in [all laugh] and honestly the last time he was there he was like the mayor, there were like 5 or 7 people, Tadgh, around you, sitting around you...

From Caoimhe's anecdote it seems like it is easier for Tadgh's friends to speak to him and approach him when alcohol has removed inhibitions or fears of not knowing what to say or how to deal with Tadgh, however the fact that they never show up at the house is clearly a source of hurt. The reluctance of these people to engage with Tadgh was probably down to what Fintan interpreted as fear of embarrassment, and fear of not knowing what to say. The stigma of YOD, especially where an impairment is more evident, had caused this potential group of support to distance themselves.

The stigma of dementia was a major issue for the participants of this study, both for the person with YOD, and for the person supporting them. Another major issue which featured extensively in the study and is especially acute for those with YOD is access to services, or, as the case more generally is, the lack of services to access. This is the subject of the next section of this chapter.

5.3 Services, or lack thereof

When drawing up this study, I wanted to get insight into what type of services the participants were using, and what their experiences had been in trying to access them. The findings, however, show that not many of the participants used services; this may partly be as they were still only in early to moderate stages of dementia, and simply did not need services. However, it may also be as a result of the lack of any type of services for person with YOD. While accessing regular services and entitlements can generally be a struggle, the paucity and near non-existence of YOD services in Ireland was an issue that came up strongly throughout the interviews.

Margaret and David were not availing of any services relating to Margaret's dementia, however they faced other practical problems, such as difficulties securing simple things like a medical card. As EU citizens at the time of the interview, they had full rights to apply for a number of supports, but found the system slow, complicated and overly bureaucratic:

D: we got to applying to medical card, because the drugs are, you pay €144 don't you, that's the maximum, so we went to get medical cards, and it's the length of time it takes to get them like, it must have taken six months to get a medical card

I: ok, and do they at least backdate the pay or?

M: no

D: no, not the medical card, no, not for that level, we got to pay for drugs

M: €150 or something

D: well we pay €144 the last few because we got on to that scheme, you pay a maximum of 144 isn't it and it's just the time it takes like, I mean we got them in the end but it's just the amount of time it takes...I think they are just that busy like, basically, there's not enough staff I think with cutbacks and things like that, so I think that's the main problem...then of course we had to get, put Margaret on invalidity pension, and the carers allowance and that were another five to six months, but that is all backdated then, we applied for carers allowance, we applied for it first and we got, we applied for invalidity pension didn't we, and carers allowance and they wouldn't give me a carers allowance, I got knocked back for it like, because she weren't serious enough, so I rang [social worker] and we went through [inaudible], and we appealed it and got it.

The difficulties Margaret experienced, both in delays in getting a medical card and having to appeal the carers allowance decision, is indicative that even access to services to which a person is fully entitled is often a struggle. The person applying must fight every step of the way for what they should be granted; a situation such as this where the person who 'screams the loudest' gets results quicker is fundamentally unfair, as not all persons are able to navigate an often confusing system on their own, or know who to contact for help. The bureaucracy and delays they experienced created a lot of stress for Margaret and David, especially David:

D: the only thing it felt like, is the time that it takes to get anything done, bureaucratically shall we say, you know, that's another thing, you think that people have no other, when something like this happens you're under enough pressure as it is without having to wait months and months for, you know to get that type of things sorted out, that's my only quibble like...you're under enough stress and pressure like, you know at home without having to start dealing with all that...I've been a bit stressed of lately trying to sort that bit out.

Margaret and David's experiences are part of a wider problem of accessing services in Ireland, and this was also touched upon by Fintan. Like some of the other participants, Fintan's involvement in awareness-raising around dementia was something he was very passionate about, and he wanted to see a change in both attitudes and the level of service on offer, and the unfairness that is inherent in the overstretched two-tier Irish health and social care system.

F: I mean there is obviously an issue of resources, you know there is an issue of resources, and you know the funding and all those terrible nuts and bolts issues, you know, because you can clearly say you know this would help this would help with would be great, this would be great, we should have this we should have this, but if the money isn't there, none of it will be there, so, you know, you then say what is there, and I suppose in that terrible, terrible way when things aren't properly provided for, then you know some people who are clear about getting at it, get the things, and those people who aren't clever at getting at it don't get them, and you know obviously education is a big factor there, you know, the, being very clichéd about it but you know an educated professional middle class person is more likely to get the information, more likely to benefit from it.

Public supports are not fairly distributed because of this issue; like Fintan points out, it is often an individual's personal resources, be they financial, contacts, or ability to navigate the

system, that determines who gets access to supports. Difficulties in accessing financial supports such as Margaret experienced were mirrored by Noírin's experiences in trying to access more practical services. Throughout her interview, Noírin was very passionate about the lack of services for persons with dementia, both for those under 65 years of age and those over 65. She struggled initially after the diagnosis with finding where she could do a driving test, and just to find out in general what supports were available for someone with dementia. She soon found out that there was essentially nothing:

N: there is nothing there really is zilch and I was interested to see about you know, I thought oh when I'm 65 I'll be dying to see what kind of services [will become available], it's a joke, it's a joke, it's a real joke, ok if you are very advanced they'll bring you to a day centre, but there is not like in England or Scotland where they have hiking groups and they have all kinds of different groups and, now, we have to set these things up ourselves

Noírin has, through her work in activism and with civil society groups, seen the supports available in other countries and the difference it makes for the person with dementia. As she outlines, there is no reason why a similar setup could not be available in Ireland:

N: in general that's just my own firm belief is, if we had a good, from once we are diagnosed early, if we have some small plan in place, and the plan that I personally think should be in place is, and that's after talking to many people, is that there is somewhere for us to go, and that there should be somebody there, an occupational therapist, who can refer us to, to some cognitive rehabilitation, you know if I broke my foot and OT would come out here and she'd look at everything in the house and she'd go, if I hurt my back she'd measure everything, you know why can't she measure, I don't say measure my brain, but in a sense, measure my ability of what I can and can't do, and see what support is available to me...I think the first point should be from once you are diagnosed that you should have minimum six weeks rehabilitation, because if you get that rehabilitation in the early stages, not a year down the road like me.

Comparing the complete lack of support for someone with dementia to the myriad supports for someone with cancer, she also points out that supporting those with dementia is not only the right thing to do for the person, but it is also the responsible thing to do from a cost-effectiveness point of view:

N: if you get those tools early on, and you get support in, support for your family, support in how to tell your family, support in, for them you know the public health nurse goes to families for, if I had cancer, believe you me, I'd have support, I'd have support, but because I have dementia it doesn't, there isn't the support...I think people with early onset or any form of dementia and get it at a younger age, there should be some kind of plan or strategy in place because in the long term it is of greater benefit for the state, it is of greater benefit to the tax payer and at the end of the day it is the tax payer that is paying for, to put people in their nursing homes, that actually could be, could do well to live at home and live well with it.

Noirín is convincing, ardent, eloquent and logical when she explains what is needed, why it is needed, and how it should work; she knows this from not only her activism work but also from her lived, first-hand experience. She is using her voice to highlight the total lack of services to ensure things will improve for those following behind her, and that they will have a chance to live better with dementia:

N: ...give the supports and to try and stay, and help them to stay active as long as they possibly can, and if they can stay in work, stay in work, did I throw in the towel too early yes probably maybe I did, maybe there was something else I could have done, maybe there was another job that I could have done that I didn't have to give up like I gave up, so you want to see, that's the kind of thing you need to see happen, so, so that would be my dearest wish, that nobody has to go through like what I had to go through.

Tadhg and Caoimhe avail of a few services for Tadhg, however his young age means that they are not all suitable. They were the only participants in the study receiving home help, getting two hours a week from the HSE, and three hours respectively from two separate Alzheimer's charities. While it took a lot of phone calls to get the help, Caoimhe explained that she was originally not sure about it:

C: ...because I was very reluctant, very reluctant to seek home help for instance now, again I thought he would be totally opposed to it, and would, you know, but I realise an awful lot of it was my unwillingness, or denying I suppose...

While accepting help was part of accepting that Tadhg would not get any better, at the time of the interview Caoimhe was hoping that the hours would increase if Tadhg got worse. Tadhg also attended a day centre one day a week:

C: ...he'll say every morning what's the plan today, where are we going today, and the three days I work I'll say I'm going to work,' but can I go with you', and go no loveen [darling] you can't go to work with me, but 'sure I'll go anyway', you know, and he's often sat in the car and waited, for an hour or more, for me, in the passenger seat, but when I say to him today is Tuesday you are going to the day care centre, 'oh right so', but whilst it is great and it is the one day like I don't need to worry about him between 10.15 and 3.10, I still have a cry leaving it because it is all 80 plus-year olds in it, I'd love him going there but if it was all his age, but I suppose that is the nature of the thing.

Leaving her 56-year old husband in a day centre where the other people are 80 years or over was still distressing for Caoimhe, despite her also saying that while he is there, she was not worrying about him. Caoimhe referred a number of times throughout the interview to Tadgh's easy-going and laid-back nature, and this is probably reflected in his enjoying the day centre regardless of the activities provided or the age profile. However, this is not necessarily the case for most persons with YOD, and the lack of suitable mental and physical stimulation is suboptimal.

One service, or rather the lack thereof, that Caoimhe mentioned on a number of occasions was the lack of a support group or specific knowledge of YOD, specifically FTD, the type Tadgh has. Having tried to find out as much as possible about it, Caoimhe still found that there was very little knowledge about it that goes deeper than just a few sentences:

C: ...what I would really love would be to find other spouses that would have somebody in the same age bracket, a support group for FTD, I'd love that, but, maybe I'll start one...I was at two different workshops and they were like advertised as 'AD and other dementias' workshops, but they really weren't, it was all AD...it was all, granny with AD or granddad, so I just said whilst it was extremely good for somebody with AD I said it was advertised as other dementia types and I said I don't even think you mentioned it, I think you mentioned Lewy body once, and, there was two girls and a fella given the workshops, and the fella said what other type were you talking about, and I said FTD, so he said well in that case you ask your GP, you know he's the one that will tell you, and that was like, maybe a month after diagnosis, it was one of my first times going and I said, well, actually no my GP didn't know anything about it, so then one of the girls said I'll speak to you after, you know, she did and she just said you are right, there isn't much known about it.

Fionn was also looking for services that were more age appropriate, and non-medical in the sense that they were adapted to persons with dementia who wanted to live well with the illness, rather than only look at it from a medical point of view. Through the hospital, he was able to access speech and language therapy, which proved to be extremely helpful for Fionn's difficulties with finding words.

M: and she referred us to the speech therapist in [hospital name], and she was excellent, like it was much more about communication than just about speech, and she worked with Fionn for a few sessions and we both went together with her and she suggested, she had a lot of suggestions you know about things that would help us to communicate and, organise ourselves and simple things like reading has become more and more difficult and just, she just said 'oh why don't you try audio books', and I use audio books and it had never occurred to me [Fionn laughs] just you know and that's, that's the experience in lots of ways, that we're doing things and the obvious isn't always, like you said about your watch, because obviously the very first thing was the inability to draw the clock, so Fionn has nice other watches but you just said I just want one that just says the time [both laugh].

Maeve explained that services for them would be something helping their day-to-day life and, much like Caoimhe, would also involve meeting other persons in the same situation with YOD:

M: ...the OT up there runs a course, a 6-week course...she said the previous course she did that the people had stayed friendly and they are going to make sort of a group or whatever you know, but, so definitely, the missing piece I think, and we've talked about this a lot, the, so you don't medicalise it, so, Fionn doesn't need you know medical care, so a lot of the services are for the eventualities of when the person needs care, so like home care or the ASI or the groups that they've suggested and we've gone along but we've kind of thought of, you know, like, the alternative, we joined the [walking group], and done some hill walking and that has been one of the best things we did last year, you know.

The non-medical approach they were striving for also helped them in terms of living well with the illness, such as for example the hill walking group; having the information and access to these types of approaches could be very helpful for a newly diagnosed person, as well as in the longer term.

5.4 Discussion and concluding thoughts

This second Findings chapter looked at the experiences of living with YOD, one of which was stigma, and the other the lack of services and supports available to persons with YOD. The stigma that is a constant companion of dementia was portrayed very powerfully by the participants, in experiences, anecdotes, or in relation to how it affects their interaction with the social world outside their family. The frustration and exasperation that the participants felt around finding or accessing services, whether practical services such as cognitive rehabilitation or day care, or other support services such as a support group specifically for YOD, where they could meet others in the same situation, were a strong thread throughout the interviews. The two themes of stigma and lack of services were strongly present in the interviews, and were included and given their own chapter as they provide a powerful illustration on the ways in which these issues affect people with YOD, and their ability to live well with the illness.

The stigma around dementia became apparent in Noírin's experience when she told friends about her diagnosis, but was told to 'take no notice', or that there were many other reasons behind any issues she was experiencing, but absolutely not dementia. Similarly, Orlaith's brother also had the same reaction, telling her she would 'get over' the illness. The denial and fundamental discomfort that these close family and friends felt when being told of the diagnosis portrays the power of stigma. The immediate reaction is one of denial, that whatever is causing the issues is something else, it is not dementia: the horror of a dementia diagnosis is not allowed to even be contemplated. The nihilistic, bleak view of dementia that causes such denial in friends and family is the same highly stigmatised version that is described in grim and hopeless terms (Hoppe, 2019), and that contributes to isolation, the false impression that nothing can be done, and that prevents open discussion (World Health Organisation, 2012). While denial may be a natural response to any type of bad news, the insistence that a diagnosis of dementia simply cannot be correct, is telling of the perception of the illness.

How stigma contributes to isolation was powerfully portrayed by the different experiences of two participants, Sean (and Aisling) and Fionn (and Maeve). Sean and Aisling preferred not to tell friends and community about Sean's diagnosis, and had told only immediate family and a select few trusted friends. Acknowledging that they might have to divulge the diagnosis at a later stage, "*...if it ever did get so progressive that I have to let people know, listen that's what's wrong with him*", they nevertheless kept it secret for now to avoid awkward situations, while accepting that this has caused a bit of a "withdrawal" from their interaction with other

people. Interestingly, later in the interview Aisling speaks about having to cut down work hours to stay at home with Sean, despite the financial effects this will have; she is dealing with the situation virtually on her own, without the ability to get support from friends and family, as they are not aware of the situation. This is causing a lot of personal and also financial pressure.

Fionn and Maeve, by contrast, decided to tell friends and family about Fionn's diagnosis, with a few exceptions. While Fionn is no longer working, Maeve is still working full-time and they have friends and family who call on Fionn most days, going out for walks, or having lunch together. This type of support is invaluable in a situation where there are very few services to begin with, as is the case in Ireland, and the assistance of friends and family are of great help to Fionn and Maeve to manage life with YOD. By being open, they have avoided the isolation that was evident in Sean and Aisling's situation, and have also enabled discussion around the topic. Maeve's comment that by friends knowing about the diagnosis, she does not have to 'overcompensate' in social settings, is a clear example of the coping strategies described by Lockeridge and Simpson (2013) to 'cover' for the person with YOD. To not have to do this, and to instead be able to enjoy time spent socialising with friends, is of great benefit for both Fionn and Maeve. It is, however, important to note that the ability to be as open as Fionn and Maeve have been is dependent on their confidence and strength to open up, and the success of their openness based on the positive response and availability of their friends and family.

In the example of Tadhg and Caoimhe, being open about Tadhg's diagnosis has helped as the small community in their rural area all help out and keep an eye on him. However, the stigma of dementia is nevertheless affecting them, as Caoimhe described how Tadhg's friends no longer call to the house, despite saying they will. Caoimhe's story about how Tadhg's friends all gather around him and have a great time together when they are in the pub late at night, where presumably alcohol has lowered their inhibitions and fear of awkward situations, give strength to the arguments that social embarrassment and social judgment are a huge part of stigma and the distancing of people from the person with YOD (Tolhurst et al., 2014).

The fear of embarrassment, and the fear of the mental health effects of dementia (Chemali et al., 2012), are eloquently described by Fintan, Orlaith and Noírín. As all three were actively involved in activism, promoting awareness of dementia and working on local, national and even international levels, it is not surprising that all three were open about their diagnosis on a daily basis. Orlaith's description of telling people in shops '*excuse me, I have dementia, I need to take a moment*' is a great example of how bit by bit the public awareness of dementia can

be expanded; by seeing a person who does not conform to the public image of dementia nevertheless live successfully with dementia, navigating shops and advocating for themselves and their peers, the nihilistic portrayal of dementia is challenged.

Nevertheless, despite their strong advocacy for dementia, both Noírin and Orlaith described being blanked by people purposefully avoiding them, and Fintan described people's shock at him openly speaking about his YOD. People's discomfort and the reluctance to move away from the image of dementia being only that of middle to late-stages of the disease (Cahill, 2018) means that stigma is not being sufficiently challenged. However, through the continuous advocacy work of individuals with YOD such as Fintan, Noírin and Orlaith, and through the type of openness showed by Fionn and Maeve, Tadgh and Caoimhe, and Niamh, the stereotypes of dementia in general and YOD in particular are being challenged, which is the first step to change.

The second major finding in this thematic section is that of services, or indeed the lack thereof. From when the first major policy document on dementia in Ireland was written in 1999, to the most recent study on YOD in Ireland published in September 2020, people with YOD trying to access services are described as faring worst of all (O'Shea & O'Reilly, 1999), and as experiencing a dearth of services (Fox et al., 2020). The participants in this study had similar, if not worse experiences, with the lack of supports being decried.

As in Margaret's experience, even navigating access to generic, non-dementia related services and entitlements such as the medical card and the carer's allowance proved to be difficult. David, as the main support for Margaret, found the process highly stressful as he was already, as he put in *"under enough stress and pressure like, you know at home without having to start dealing with all that"*. Margaret and David were lucky in a sense in that they had a contact in the Memory Clinic that could help them deal with their issues, and were able to resolve the problem with the carer's allowance; however, the delay in getting a medical card meant expenses that they would not get back. This ill-functioning system breeds not only stress and discontent, but also (even more) inequity into the Irish social care system, as those without the knowledge, power or ability to navigate or challenge a bureaucratic system may end up with a poorer access to their entitlements, or even completely without them.

In relation to services that were specific for persons with YOD, a major finding of this study was the strong feeling that there was a real and pronounced lack of anything suitable. The findings relating to services reveal that many participants felt the lack of a support group specifically for those with YOD; being able to speak with other people in the same situation, or

even spend time together socially, was sorely missed. Similar to what Mayrhofer and colleagues (2018) discovered in their study on community-based service delivery for persons with YOD, social connections and social networks could be of great benefit post-diagnosis as the person, and their family, re-constructs their sense of self, and adapts to their new reality. Fionn and Maeve spoke about interacting with other people with YOD as ‘the missing piece’, and were planning on attending an occupational therapy course partly to meet other people in the same situation. Caoimhe spoke about the need for a group specific to FTD, as this type of dementia often manifests markedly different from e.g. Alzheimer’s Disease, and had found that even in dementia workshops she attended there was limited or no knowledge around FTD specifically. Haase (2005) in his pioneering study on YOD in Ireland also highlighted this gap, recommending that specific support groups be set up for people with YOD (Haase, 2005).

Tadhg was the only participant who received weekly home care, and he also attended a day care facility once a week. However, this facility was for older people, and Caoimhe’s comment that *“I still have a cry leaving it”* because the other attendees are all 80 and over, is a poignant and distressing illustration of how unsuitable older persons’ care facilities can be for persons with YOD. While in this case Tadhg was happy to attend the facility, the fact that it was only for a few hours once a week might be a mitigating factor. As Bakker and colleagues (2010) showed, being a young person with dementia in a setting for much older adults, which in their study was a nursing home, created upset and distress for both the person with YOD, and his spouse; Lockeridge and Simpson (2013) also made similar findings, where support persons of those with YOD described services for older people being used by the person with YOD as wholly unsuitable.

Noírín eloquently pointed out the lack of services such as cognitive rehabilitation for those diagnosed with YOD. Comparing the lack of supports for YOD with the supports available to a person with cancer, she highlighted in an unequivocal way the degree to which those with YOD are left to fend for themselves. Noírín’s rich description of what services could, and should be available and how they would benefit the person with YOD echo the study carried out by Bjoernstad Tonga and colleagues (2016) which showed that structured cognitive behavioural/rehabilitation programmes could be of benefit to persons with YOD. In this PhD study, an example of this was Fionn’s visit to a speech and language therapist, who provided him with simple but highly effective tools, such as using audio books when it was difficult for Fionn to read, or to use a digital watch instead of a traditional one, as he struggled to tell the time. With such simple but effective supports in place for people with YOD, it would, as Noírín

elaborated, be possible for the person to work longer, stay in their home longer, and participate in society more, meaning more benefit for society as a whole.

The lack of services, whether in terms of day care facilities, targeted therapies such as cognitive rehabilitation, occupational therapy or speech and language, YOD support groups for both the person with YOD or family members, or a more effective, accessible and equitable social care system, was a major finding in this study, and appeared in relation to other issues throughout the interviews. Even basic practical interventions such as tools for organising and planning have the potential to make a difference for the person with YOD, and support their abilities. For example, busy with her life in general and her advocacy work in particular, Noírin mentioned her diary on a number of occasions throughout the interview as a key part of how she organises and keeps up with her day and her schedule. While she still makes mistakes, or forgets things, the diary helped her to control and organise her life, and contributed to being able to live well with dementia.

This chapter has focused on lived experiences of having YOD in Ireland. Both the issues of stigma and the lack of services are closely intertwined with the next chapter, which looks at the personal sphere of dementia; they affect many of the issues that pertain to the lived experience of YOD. The next chapter, the third and final Findings chapter, will discuss findings made around employment, children, and living well with dementia.

CHAPTER SIX – FINDINGS AND DISCUSSION III: PERSONAL SPHERE AND YOUNG ONSET DEMENTIA

6.1 Introduction

The focus of this chapter is on participant experiences of YOD that relate to the personal sphere of life. Many of the findings from this study were concerned with the individual realities of YOD – employment issues, concerns around family life, particularly children, and how to live with YOD. These issues, often highly personal, provided a rich portrayal of life with YOD and all impacted on how the person with YOD learned how to adapt to their new situation, and how to live well with YOD.

6.2 Employment

The impact of dementia meant that only one participant, Fintan, was still in employment. As his employment experience was very different from the other participants, it will be discussed in the later section on living well with dementia. The other nine participants had either retired before the illness (Margaret, Noírín) or left employment because of their YOD (Sean, Micheál, Seamus, Fionn, Orlaith, Niamh, and Tadgh).

Their experiences of leaving employment were generally poor, with the problems caused by the YOD not well understood by either their place of employment or by themselves, especially as the issues often came before the diagnosis. However, the loss of employment was keenly felt, financially to a certain extent but also in relation to the role employment plays in a person's life – as an occupation, a social outlet, a stimulation, and a part of a person's overall identity.

Tadgh ceased working very soon after his diagnosis, on the insistence of his employer. At the time of our interview his wife Caoimhe spoke most of the time – when asked questions, Tadgh generally shrugged or did not engage, coming across as finding the experience quite boring. However, in the following exchange, his demeanour changed completely:

I: So how does it feel, has it impacted on you Tadgh, on both of you?

C: What do you miss most about, since you got sick?

T: Not working.

C: Not working.

I: Not working, ok.

C: He always says that.

I: And what did you work as Tadgh?

T: I was working in [pharmaceutical company], then they let me go because [inaudible] never got a penny off them.

It is striking that Tadgh, who had up until that point been obliging but quite uninterested, suddenly focused in on the conversation immediately, and put into words that he really missed his job. Caoimhe explained the background to Tadgh's dismissal from work:

C: ...The doctor said his work needs to be informed, and he can't drive, so that was, I informed work, that was a Friday, and on Tuesday, I just left a voicemail, and on Tuesday they phoned back and they had noticed changes, you know and that he was making mistakes and not following directions, and they took him in to the nurses station on two occasions, but he told them he was ok and that he was fine and then they kind of let him back again, one or two of his colleagues then as well would have kind of sort of said no Tadgh this is what you do, you know, kind of, to help, so, they kind of covered for him without realising it if you like, but we'll say, the 21st of April would have been when they were officially informed, and he was let go from work about the 5th of May, 4th or 5th of May, so you are talking about another week.

I: Ok, so it was fairly...

C: Very, very rapid, yes, and health and safety, that was their reason.

Caoimhe was initially very unhappy with the way Tadgh was treated; the extent of the diagnosis was not yet clear and she did not understand how they could simply just let him go. He had driven himself to his diagnostic scan, and going from that level of independence to being told to not return to work was a shock. At the time, Caoimhe was exasperated with the HR person, but looking back understood the rationale of the company:

C: well I suppose, we were called in, and I was like, very, what's the word, possessive you know or how can you just do this to him like, he didn't, because the way he was let go, basically he worked a Monday and Tuesday, and he was told, I got a phone call to say for health and safety we think it's best he doesn't come in tomorrow, and I said oh what about Thursday and Friday, Monday was a bank holiday, the May bank holiday, they said well we'll call you back, we'll see, but you know given the type of job he is

doing and, and you know she was kind of, you know 'I'm just passing on the message I'm sorry' kind of thing, and we will phone, we will call you back, there will be a review where he'll get to see the doctor in there, I mean I kind of get it now, but in the beginning I was like, I mean he is here 17 years how can you just do this to him, but what could they do either, you know...

While Caoimhe understood why Tadgh could not work anymore, he clearly missed working. From Caoimhe's descriptions of him before he got sick, he was someone who got things done and was a hard worker:

C: yes, and [the dementia] just taken away like, everything in my opinion, he is still here, but he is not, there is nothing, [inaudible] look the same in my opinion, he put weight on, he was the most sensible, he could paint anything, he could put up tiles, he would make furniture, he'd drive you anywhere, he would, couldn't do enough for you, and now it is like, you know, loads and loads of deficits, but just happy

Caoimhe also refers to Tadgh speaking about work, and missing being at work:

C: he has always said, I should be working, it's not fair, he'll say that now and again, it's not so much now but in the beginning

Not working anymore had left a void in Tadgh's life that is evident both from Caoimhe's description and his own clear contribution. It seems that going from always being busy with something, both in work and outside work, to being at home and having very little stimulation in terms of suitable services, meant that Tadgh missed his employment greatly. In addition, Tadgh's loss of work also had a financial implication:

C: I said can he be made redundant and they said no, because the job is there, he is just not able to do it, so there was no redundancy.

I: But he got some form of pay.

C: Well, illness benefit I suppose they call it, they did pay him for, they did say 13 weeks to begin with but they actually paid him for 26, and he is now getting disability benefit, but I mean, the life insurance he had was with his work, that's gone, the health insurance was with work, that's gone, and plus there is a deficit of about minimum €300 a week, you know, that...

Moreover, as Tadgh was the person who looked after all financial aspects and paid the bills, Caoimhe not only had to get a grasp of all this herself, but also discovered that their mortgage had gone unpaid as Tadgh's illness became worse:

C: yes, yes, I never paid a bill in my life before this, very few, you know, he would have done all the bigger, mortgage, because that was 11 months in arrears when I finally started [paying the monthly mortgage bill] and of course I noticed this before he'd gotten officially diagnosed, and I was like what the hell is going on and, screaming at him one day, and he goes what do you want me to do, I said I just want you to be Tadgh [laughs] you know, so...

The general air of not caring about anything and letting things such as mortgage payments go, which had led Caoimhe to think that maybe Tadgh had depression, was obviously very frustrating for Caoimhe. The fundamental change in Tadgh's personality and behaviour is clear in her exasperated plea to him to just 'be Tadgh' – to go back to the person he used to be. As the reasons for this behaviour became clear with the diagnosis, Caoimhe was fortunately able to solve the mortgage issue without too much trouble.

The financial issues experienced by Tadgh and Caoimhe were not as clearly expressed by Fionn, however similar issues were still there, as was the dramatic change created by having to give up the working life because of the illness. Fionn spoke about how his diagnosis of YOD changed his life, and how there are now many things he cannot do, including work. Fionn had been self-employed, but working for a friend. Because of this connection, before he was diagnosed Maeve was able to ring the employer and speak about Fionn's difficulties, to clear the air:

M: ...at some point anyway we decided that I would ring [name] and have a word with him, and he said, you know, basically he said there is a problem, you know which we, I suppose [name] would have been the other person who sees Fionn all the time, you know, like I see Fionn more than anyone probably at home and that, but while we had our routine and I wasn't getting the signals if you like of what might be seriously going wrong here, but I suppose [name] could see on the technical side maybe...

Fionn had tried to keep going but, as he describes, at a certain point he knew he would not go back:

F: I suppose I knew things, wasn't right but I remember going off, going out from the office and I knew that evening that I'd probably never, go in, well that I wouldn't work there ever again and I didn't, I just knew...

M: if you remember back actually, I'd forgotten, you got very anxious about it, do you remember, there was a lot of anxiety around work, and [employer name], and you know

...

F: ...I had four things like this, you know [grabs sheets of paper on table] and I wanted to have them in the right order, and I couldn't get them into the order, you know, and even though it was a number on them, I still couldn't do it, so that was, I knew then, that evening I said to myself I probably will never work here again...

Fionn also mentioned the fact that they now only have one income; prior to getting sick, he had what he described as a 'reasonable income', and they had bought a new house shortly before the illness. Nevertheless, they were able to manage on one income and the loss of employment, and the break with his former life which this represented for Fionn, was probably the more deeply felt issue around work.

Sean, who was let go from his place of employment just before he got sick and was taking a case for unfair dismissal, also verbalised that he missed contributing, and earning money. While his wife had always been the one in charge of the family finances due to Sean's dyslexia, he had nevertheless always contributed and had his own money, which he could use as he pleased once all the bills were paid:

I: ...do you miss being able to contribute?

S: yes, that as well and that like you know...if your friends are there like you know, it is nicer and that like you know, if I go up to the pub or well, I don't do it now anyway, but anyway...

Aisling also pointed out that having always worked for a living, Sean was getting bored at home, and with nothing to do he mainly waited for Aisling to come home from her part-time work as a health care worker:

A: I was finding when I'm doing the three nights he's fine, come the fourth night, it's, are you in work again tonight, because he's here all day on his own, now he goes up and watches telly with, I think he'd be delighted to get rid of me out of the house at

night time [all giggle] but it's, then when I come in and he'd say are you not going to sit and talk to me for a while and I'm after being up all night

The combination of not working and being at home a lot due to the dementia meant that Sean relied on Aisling for company, something which was difficult as she was still working. In this respect, Sean's loss of employment affected them both.

Issues around leaving employment and feeling a certain loss of purpose were not the only issues related to employment and YOD; some were of a more practical nature. Micheál had to leave his professional services company as a result of his illness, which caused a lot of logistical problems for his clients – this created a lot of pressure as solutions had to be found to get around legal issues:

M: now, I had employees who were dealing with certain matters but when I had to close down it was quite a lot of matters that were not completed by then, and as a result a lot of former clients reported me to [Professional Body], because now most of that work was in relation to [work-related issue] but the [regulatory office] was aware that I no longer had a practicing certificate and they would not accept any correspondence from me, so I had to in all of those cases I had to hand the files over to another [professional services company] who was practicing...see another [professional] took over my practice but, and he was supposed to take over everything but when he did go into the office he pointed out that he was not going to deal with matters which had not been completed.

This whole chain of events was very stressful for Micheál, and his son had to step in to help solve the problems:

M: ...only a few things that are outstanding now, another [professional services company] who were contacted by my son have agreed to take over all outstanding matters to deal with everything... I did [find it stressful], yes, particularly due to the fact that I could not deal with it because the [regulatory office] would not accept my correspondence, and then I had to get the consent of the client to pass the file to a [professional services company] who would do this work...

It was a relief to Micheál that the problems eventually got solved, however the snowball effect his illness had on his company and the people he represented was extensive.

Niamh also experiences issues with carrying out her work. As detailed in Chapter Four, her symptoms became evident in work as well as in her private life, however, her place of work was not very understanding or sympathetic to her troubles:

N: ...horrible stuff too, emm, my supervisor used to bring me up to the furthest biggest window that we had in the place, and I got regular bollockings for want of a better expression [laughs] whatever, and then you know, that went on for probably quite a while and I just, you know, I just thought, I don't know what I thought but I was still trying to do my best to really work, and then another supervisor came in on top of that and you know, that kind of happened as well, and, and at one point I couldn't finish off a calculation in, at work, and, and I said to her could you just help me with that she said no, no! [mimics annoyed voice] and all this kind of thing

Eventually Niamh went to see the doctor at her place of employment. The doctor tried his best to help her but came to the conclusion that she should not continue working:

N: ...we have a guy that looks after us in, in terms of you know if you are having any trouble at work, he's there to help and all that kind of thing and they really tried to help me as well, but that didn't really, you know...I suppose I cried and I did all kinds of things you know [laughs] at that point and, he, you know, because it was kind of emotional, you know, having to sort of say these things over and over I suppose to some degree, and he...he was just really so nice the whole way through it, you know and I met him over maybe three or four times, and he was very nice and talked to us and really like, you know...he is a lovely guy actually, but he was the one that said she is not to work again.

Niamh was eventually let go from work with a disability payment. While she found the doctor to be very understanding and helpful, it was clear that the management team's behaviour had not been adequate, compassionate or helpful. However, Niamh did not miss working and was very philosophical about her experience.

N: I suppose a bank employee that couldn't count wasn't too much, wasn't useful, but I'd say that, that I could have continued to work but I'm quite happy not to be working you know, because life is really nice [laughs] you know because it was always like driving up and down to work and whatever so...

Of the participants who discussed employment, Niamh is the only one who was expressly happy not to be working anymore, and instead saw her life without work as free to be filled with other things.

Employment and related issues are one of the main things that sets YOD apart from LOD in terms of the lived experience, and the premature exit from their employment was in general not a happy experience for the participants. Another main difference between YOD and LOD is that of children. Those with YOD are much more likely to have younger children, who are still dependent on their parent in a number of ways. This is the subject of the next section.

6.3 Children

Of the ten participants in the study, three did not have children (Seamus, Fionn, and Niamh) and the remaining seven did. No participant had children who were younger than in their teens, but how the children were affected by the diagnosis, how they would be affected when the illness got worse, and what legacy the dementia would leave were all concerns for the participants.

Orlaith spoke at great length about her children; they were central to all her experiences, and were always at the forefront of her mind. She had two sons, both in their early twenties. One of her sons had autism, and both had recently gone through difficult periods in their personal lives unrelated to her illness. Her main worry was that she would not be able to be there for them when they would be on their own but needed her the most in relation to their problems. Both her sons were old enough to realise the gravity of the situation, but they were also young enough to get frustrated about the way the dementia affected Orlaith in their daily life together. Orlaith worked very hard to not let the dementia affect the boys too much:

O: I find the boys like, you know [son A] will say to me oh I was talking to [friend's name] or [friend's name] today or she met you the other day and I'm going 'who is she' and I need him to put her into context with where I saw her and all the rest of it, and he naturally is getting on with life and he can get impatient and he can tut, which can be extremely hurtful at times, it's like, but I don't have a sign on me saying [I have dementia], so I'm sure for the guys, they do get frustrated that mam doesn't remember this or they've told me 10 times and they need to tell me the eleventh time, I work very hard on trying to be as well as I can when the boys are around.

Orlaith's worry about her children was compounded by the fact that she was separated from their father who the children did not have much contact with, meaning that she was the main parent in their lives. Her sons have had their own problems, which made her illness even more difficult for her to bear as she worried about them and how they would cope without her.

When she told them about the diagnosis, they reacted differently:

O: [son A] would be the guy with [autism] and the anxiety and all the rest, 'ok, I'm sorry you have it' but in his mind I'll be grey, even though I'm grey already but, I'll be old, I'll be granddad's age, like my dad is 82, so, 82, so in his mind he's going yes I'll be through college and I'll have my family and I'll have friends and I'll have my own home so he's kind of worked it out going down there, it has come up a few times and I have been very honest with him and said to him you know we could be as little as two or three years depending, and he'll go 'yes but we won't think about that yet mam'...[son B] then, was very, very angry, very angry, I mean he spent about 24 hours up in the shed and he was banging and knocking and slamming and cursing and all the rest of it, he was going out with a girl at that stage and his big upset was, not knowing how long he had me, and mam is the only one that's been in our court and we know we can depend on, if she goes before we are really grown up, who is going to do that for us, he would be very upset that I mightn't get to meet his children [gets emotional] and I'm saying there's no reason to run out and have them now [laughs] you bide your time.

Knowing that she might not see her sons' future families or grandchildren, or help guide them to a stage where they can stand on their own two feet, was a source of great pain for both Orlaith and her sons. Orlaith's worry for their wellbeing, and her sorrow at knowing that she was going to be the cause of pain and upset for her boys, was a constant theme throughout the interview:

O: ...what I find the hardest when I sit down and think about is that, two things, one that I'm going to be the cause of this upset and hurt and sadness and grieving [gets emotional] and two, that as I become less available to them they have to deal with more, so it is really horrible kind of, there is no out, if you like, of it, and they have to deal with it and they are going to have to make decisions in the end where I won't be able to make them for myself, that's tough, I imagine it is tough on any child, but to be kind of in your 20s is [trails off]

Despite their age, her sons had shown maturity and bravery which had surprised and impressed Orlaith. At the same time, it made her sad in the sense that they should not be worrying about such things at their age:

O: ...they spent about two hours one day literally 'mam what do you want, who do you want to mind you, when you can no longer speak mam, which of us will speak for you' [gets emotional] you know, 'remind us mam of the flowers you like say what we want to put on your grave' [still emotional], I was gobsmacked, that's a tough place to be, to go...

While Orlaith was honest and open with her sons about the illness and what will happen to her, she was still trying to show her best side to the boys to prevent them worrying. Nevertheless, she still acknowledged the fact that they needed know what will happen in the future, and both her sons seemed to have taken this on board:

O: ...they are really hard things because [gets emotional] you know the stress of it is impacting you, and you are trying to not take it on, yet you know these guys are watching you and they are waiting for you to disappear, and disappear, and disappear...[son B] said 'I know no one can tell me how long mam has, and how she is going to go, but, I know it is not going to be a nice death, and, will she recognise me the day I graduate' [gets emotional] so he really had taken on board that it is probably sooner rather than later, you know I have offered them kind of counselling and, [son B] would kind of be 'you're getting on with it mam so we'll get on with it'.

Orlaith's involvement in awareness-raising and advocacy about dementia and speaking out about it on both a local and national level had also included her sons, and while she was glad that they had participated and supported her, she also worried that it was putting a burden on them, particularly on Son Y who was struggling with college:

O: I don't know how much of a burden it's really been on [them]...they tell me they were very proud of the fact that even though this is happening to me I'm trying to help somebody else, ...at the end of the day I have to hope that my parenting will help them to be the people they need to be to go on and live...

The boys are very clearly the centre of her life, and much of her time was concerned with worrying what will happen when she was no longer present, either mentally or physically. Orlaith hoped that the love and her strong bond with her sons would be enough to prepare them as much as possible, in as good a way as possible, for what is coming:

O: ...I say to them 'guys, you know, if we never leave anything unsaid at the end of each day, then we are constantly' you know...there is an area around anticipatory grief that kind of, there, over a long period of time if a parent or anybody is kind of dying close to you that there are things, so that is something I'd certainly would be kind of looking in to and seeing that they can do as much to be not carrying the burden, you know, and of course it depends because it is very different if they are out and in a stable relationship with somebody to if they're in college and trying to do their exams and their degrees, so although it is unknown for me, it is very unknown for them because they are facing the fact now of, well where will our home be when mum's not able, will we have a home, is it going to be a college room for the next three years [gets emotional] that's shitty stuff for them to have to deal with, it really is, so I try to say to them, you know, do what you can to prepare for your future and then don't let it take today from you, so...

Orlaith's ongoing worries for her sons have affected her in the sense that she was trying to 'carry the burden' of her illness for them both, while carrying it for herself, as well as also navigating day-to-day life with YOD. The emotional labour which she was performing for her sons, and for herself, was very strenuous and while Orlaith was very passionate, upbeat and determined throughout the interview, this aspect of her experience of YOD was very dark.

While not as verbose as Orlaith, Nóirín still referred to her son during the course of the interview, and how difficult her illness had been for him. Nóirín and her husband only have one child, and this fact played on her mind throughout:

N: I should say to you really at this stage that I can't tell you the devastation it was for my husband, for [son's name] ...the devastation it is for your family, you know, and I am one of nine, so, all my siblings have different, but it is different we have only one son, one child, so it was very difficult for him.

Nóirín worried that the difficult period after her diagnosis was affecting her son negatively, and was afraid that the burden her illness put on him was too much at times, having a real impact on his life:

N: oh I think it is an emotional thing because my son, he was just finishing his, he had just finished his [professional qualification] and he was in the process of applying for jobs and, he had completed his traineeship and it was very difficult for him, it was very difficult for me I remember he was going for an interview and I remember I felt within

me that it was my, it wasn't, it was, he didn't get the job and I just felt it's the pressure on him, actually it wasn't he ended up getting another section within the same company so, you know...

While she was worried about the future and also worried about being a burden to both her husband and her son, Nóirín nevertheless made sure that everything was organised as well as it could be, especially as her son was an only child and would not have a sibling to share any problems or difficult decisions with:

N: there's stuff like that and then, then you are a worry to your husband, you know where are we going what's our future, is everything in place, [but] we are responsible citizens and when you have only one child you make your will a long time ago and all of that was in place.

Very organised and practical, it was no surprise that Nóirín had made sure that issues that could be sorted, such as wills and future planning, had been carried out. Similarly to Orlaith, she had strong concerns about what would happen in the future, and preparation and organisation may have been a way of allaying the worries caused by her orienting herself towards the future.

Tadhg and Caoimhe have three sons, two in their mid to late teens and one in his early twenties. After Tadhg's diagnosis, a dementia charity offered counselling to Caoimhe and the boys, and while Caoimhe accepted and found the few sessions very helpful, all three sons refused to go. They were aware that something had changed in their father's behaviour, but nevertheless reacted differently to his diagnosis:

C: ...the oldest, well he's moved out now but, very angry, that was kind of how he dealt with it, the middle guy who is in college, he's 19, he was my rock kind of, still is really, you know kind of, because I mean a couple of times I said am I imagining this, and then [son B] would say no I noticed now he did such a thing yesterday and, you know, and, so then we kind of started, I said if you notice anything will you let me know and vice versa kind of, and, so like his, no none of them have cried, that I've seen anyway, now that's the one thing I kind of wish they did, I suppose being boys, but, yes the middle one is very logical and very good and, you know, if he sees anything or notices anything, you know I could now go out with my friends if he was here, you know, and he kind of knows the medication he's on and all that, and the youngest then is, no tolerance, or very little...they used to be the best of buddies, I was the outsider, and

now it is, you know, I wish I had old dad back, at times, you know, so I kind of say, you know, like he's still there, even though I [inaudible] but I don't want them to regret anything, you know

While it was clear that the children all reacted differently, and were dealing with the diagnosis in different ways, the way son B had been and continued to be a support for Caoimhe was an example of how children can be a support for the parent. Having at least one son who could help with practical matters, that she could talk to about Tadgh, and who could even provide some respite at times, is a great source of comfort for Caoimhe.

The changes in Tadgh's personality had been and continue to be difficult for all the family. Caoimhe had put much effort into trying to explain that it is the illness, and not their father, who was behaving unusually when something happens. However, it is not possible to protect children all the time and the following anecdote from Caoimhe shows how the dementia sometimes puts children in situations way beyond their ability and which they should not have to experience:

C: Well on holidays, we went to Portugal last year, there was an issue with my youngest son, the three of us went with another friend of mine, and the following day there was about five more coming and the day after, there was like 13 of us in the end, but the four of us were there the first day on our own, he [Tadgh] was inappropriate beside the pool one day, where he saw two topless girls and went like, well it was my son that ran for me and he was just like going to, he didn't like do an awful lot but, I mean, it was, the opposite, in all the years I ever known him, unless he did it very privately, and I'm not saying there is anything wrong with it, if, whatever floats your boat when you are on your own but like I just said, to my son I said look it is totally inappropriate for him to do it there and it is his illness it is not him, and like but, there is still parts of me that sometimes hates the person he is almost, and I, I mean, I try and never ever show him that, but that's huge for me at times, like it is hard, if it was a friend of mine and it was her husband I think I would be 40 times better, but because it is your own, or, you know, if he was older, you'd sort of excuse it like, yes.

This incident was traumatic for both Caoimhe and Son C in that it was not only uncharacteristic and not what Tadgh ever was like, but also must have been very challenging and embarrassing for a 15-year old to experience, and difficult to understand. Caoimhe's very powerful statement, "there is still parts of me that sometimes hates the person he is almost", illustrates how radically Tadgh had changed, and the source of sorrow that this was.

Sean and Aisling have four children, two sons and two daughters, all in their late teens and twenties. They are a close family, and Aisling told of how her oldest son reacted when he found out that Sean had Alzheimer's:

A: while I was in the waiting room I texted [son A], and I said dad is getting the results of the scan today, we weren't expecting it ...he rang me then because I wasn't texting him back, and I just said, I didn't think, I just said look your dad has Alzheimer's, the next thing he goes to pieces in work, his boss wouldn't let him drive the bike home he ended up leaving him home, it was a stupid thing I did, stupid thing I did.

Aisling had not really considered that her oldest son would have such a strong reaction. The rest of the family were all told later the same day that Sean had been diagnosed with dementia, but all reacted differently.

A: so when we got home here, I just sort of felt if I'm honest with you, [son A] turned it into his own grief, I mean Sean was sitting there, [son A] was sitting there, crying, [daughter A] was sitting there, [daughter A] didn't cry until everyone went to bed, [daughter B] has never cried, and she probably is very close to Sean, but she's never cried.

Sean spends a lot of time at home since he got his diagnosis, as he does not like to leave the house on his own. This has caused some tension as he gets irritated at the children, especially his youngest son, who had been going through a tough time of his own in parallel to Sean's diagnosis, as Aisling explained:

A: ...sometimes I find he even gets frustrated at the kids, but they, my kids were never one for, how can I put this, now, we're going on holidays I won't be worrying about the place being smashed up or anything, they were never like that, they are home birds, but sometimes is annoyed because he'd like to see them out more often, [son B] doesn't socialise at all, and then this year as well we discovered he was gay, so there has been a lot that we have gone through in the last year...[son B] has his own emotional problems, and then as I said it came out then that he was gay, but that hadn't got anything to do with the problems he had, it was just something I discovered while I was trying to find out what was wrong with him, you know.

Son B's mental health problems were an additional layer in difficulties that mainly Aisling was dealing with at the time of the interview, with little help from Sean. She recounts throughout the interview her worry for her son and how he had stopped interacting with his peers, and

her attempts at helping him were a constant preoccupation. She was handling this issue mainly on her own, as Sean was limited in his ability to help, and this added another layer of stress onto Aisling, who was already coping with a lot on her own.

Fintan's experience with his children was quite different from the other participants. He has two children, a son and a daughter, also in their late teens/very early 20s. He explained that in terms of his diagnosis, they had come to terms with it as well as can be expected:

F: I suppose for my children first of all, they I think were frightened, a bit disturbed, you know understandably, what does this mean, and it's taken them a little bit of a while to step back that little bit and accept that oh this maybe isn't quite so you know, traumatic, immediately traumatic, as they might have thought initially... both of them are still of an age where it is a bit scary for your parent not to be well, you know, they still, they are not quite out in the world themselves and established and all that so it is oh God a bit of uncertainty for themselves, so, you know I understand that and I think broadly speaking they are coping with it very well, and they also do have some good significant adult relationships with other people that we were kind of careful to cultivate and make sure they had those kinds of people in their lives, so you know they've, I think they've probably as good a security with the situation as could be expected.

Fintan and his wife had raised their children to be independent and with good attachment, and the example he gives of them making sure that his children had other significant adult relationships speaks volumes to this. Nevertheless, Fintan's high profile of being outspoken and active in raising awareness at first seemed to bother both children:

F: I think they do have a certain discomfort with the fact that I am being public about it, which is obviously them feeling the shame/fear thing to some degree, you know, and I'm kind of just trying to say to them look the reason I'm doing this is because there is no need to have that reaction or to feel like that, you know, it's inappropriate, it is not necessary, so you know I am trying to help them through it in that way, I think it is probably also you know to some degree true, I do get quite a lot of good response in terms of friends or whatever emailing and people going on Facebook and whatever to the interview, and I think my kids saw that and it made them kind of say oh, you know, so it made them see that there was something that was positive about that, I think.

Fintan's ability to guide his children first through the news of the diagnosis, and then the awkwardness felt at his public profile, made the journey easier for them and also helped them see that a lot of the awkwardness they felt was actually part of the stigma around dementia. By gently pointing out to them that the immediate trauma or shame/fear that they felt was not rooted in the lived reality, he had effectively and comprehensively removed the discomfort and unease they felt. Fintan's advocacy work, insights, and general behaviour provides a strong contrast to the stereotypical image of dementia, and instead presents a picture of how living well with dementia is both possible and probable. The area of living well with dementia is the next, and final, topic in this chapter.

6.4 Living well with dementia

As the findings from this study have shown, life with YOD for the participants has many challenges, has brought uncertainties and difficulties unique to the situation of being young and having dementia, and has fundamentally changed their lives. Participants reported difficulties with coming to terms with the diagnosis, going through a very difficult time of accepting their new reality, and struggling with day-to-day life. However, there were also participants who, after grappling to come to terms with the fact that they have YOD, and everything that brings, were able to adapt to their new situation, employ a number of strategies to continue with their day-to-day life, and who were able to live well. While not all participants had this experience, it was nevertheless a strong finding in many interviews. This positivity may stem from the fact that a number of the participants were in early stages of the illness, or had a better support network than others which facilitated a positive outlook, or that the numerous participants who were also advocates for YOD were more 'at ease' with the illness and could speak out in a freer and more positive way. It was, nevertheless, a striking finding that reared its head time and again; as 'positivity' and 'living well' are not words often associated with an illness as stigmatised and feared as dementia, it felt important to capture this finding and to highlight that living well with YOD is possible.

Margaret and David took Margaret's illness in their stride. Margaret was calmer than David about the illness, but overall they were both happy to enjoy living in the moment, and not worry too much about what would happen in the future. This approach was evident already at diagnosis, which Margaret described:

I: Ok, and how did you feel Margaret, did you think that was going to be the diagnosis or?

M: Well, I just sort of thought well, it's not going to, go tomorrow...I know, at some point it will get worse but while I can do what I can do, I'm happy.

I: That's great.

D: No she's been brilliant, she sees it like that, absolutely brilliant, far better than I'm sure I would be [M laughs] or will be.

Both Margaret and David were gentle, soft spoken and quiet, but nevertheless strong in their positivity; throughout the interview it became clear that this was part of their personalities. Margaret described how their relationship has been affected by the dementia by explaining that she does not want to be mollycoddled, and their relationship is still the same in that they face the illness with positivity, calmness and resolve:

M: We laugh it [the dementia] off.

I: You have a very positive outlook both of you.

D: Yes, I forget something, if I forget to post something or, she'll say it's me who's supposed to have trouble with the memory, dementia, not you [all laugh].

I: Yes so you both, positive outlook.

D: Yes well you've got to ain't you, what else are you going to do, there's nothing else to do.

M: We've always been like that.

D: Yes, there's no alternative like, like I said curl up to a ball and die...you just get on with it, just drink more wine [all laugh].

As Margaret had retired, she now spent a lot of her time in their rural home baking and cooking as she had a culinary background. Both her and David's personalities came across as warm, quiet, and calm, and taking their life day by day and not worrying about what was going to happen in the future seemed to be how they had always lived their lives, in accordance with Margaret's statement above.

Fionn and Maeve also faced the illness together, and had gotten friends and family involved to help. Not wanting to focus only on YOD as a medical issue, they instead looked at things from a social and physical angle, and actively tried to adjust their lives to give Fionn enjoyment and satisfaction out of his day-to-day existence. Maeve described how the lack of social outlets for

younger persons with dementia originally led them to reach out to family and friends for support instead:

M: ...and there, don't seem to be services if you like in that kind of social side, interaction, and we've kind of engaged Fionn's friends and family, you know because I am out all day in work, so there are a number of people we've called on really, you know, and I'm sure there are other people in the situation you know that maybe don't, you know, have the same get up and go to do that or, because some of the people that we called, like say [friend X and friend Y], oh and [friend Z], [friend Z] lives quite nearby and he said he'd sometimes passed and wasn't sure whether to call in, or he'd be intruding, and was delighted you know that we said it would be great, you know if you are out for a walk drop in and, and then they did that, he called a good few times with his dog and they went up [local hill] and, so it's, I think that is maybe where the missing gap from our experience would be is the, the meaningful something to do.

Here, the reluctance of friend Z to call in, unsure and worried that he might be intruding, was turned on its head through open communication; friend Z approached Fionn and Maeve, despite his awkwardness, and Fionn and Maeve's delight to accept his offers of visiting had created a whole new social outlet for Fionn.

Fionn and Maeve have visited their local day centre for people with dementia, and while they thought that it seemed fine, it had the same problem as what other participants had experienced; it was nearly exclusively very old adults who were mainly just sitting in a room. While they would consider going to the day centre, Maeve summarised their feelings on it:

M: ...and our feeling was, at the moment we'd rather, like, it's better to meet [friend] and go for a walk than sitting in a room drinking tea like with, tea with people that you don't really, that the only thing you have in common is Alzheimer's, do you know what I mean, so, we'd rather not be, in the same vein of don't over-medicalise it really isn't it, you know, it is about, it is just about finding meaningful things, because I think in Fionn's case what is affected is the ability to do things, you know so... because it is not so easy, say Fionn before was into running and is considering taking that up again, you can't just join a running club and you know, as if nothing was wrong, because something is amiss, you know, or even with the walking club we both go, you know I wouldn't be happy for Fionn, for you to be on your own, because if there is a weather change and you have to change all your gear, that would be a problem.

This quote shows that while acknowledging Fionn's shortcomings and realising that life cannot continue as if nothing is 'amiss', they nevertheless have focused on what Fionn still *can* do, rather than looking at things that were no longer possible, such as joining a running club alone. Maeve and Finn have joined a walking group together, and a friend they made in that club now walks with Fionn regularly during the week, in addition to regular visits from friends and family. To further motivate Fionn to stay active, they decided to get a dog:

M: So, and the things are simple like in terms of exercise and you know Fionn's initiative has been impaired so we got the dog, you know [laughs] so today you went out with [friend] and you went for lunch and if the dog hadn't been here you mightn't have gone out for a walk afterwards you know.

F: No I wouldn't, no.

M: But the dog looks at you and you kind of go he's going to go bonkers if we don't bring him out, so now you have a routine where you go down to the beach with the dog, you know...but in terms of just getting out for a walk so, things that would encourage us, so we joined the [walking club], and now Fionn has his [walking club] friend during the week, so.

While both Fionn and Maeve were doing their utmost to make the best of the situation, it was not always easy and not all problems are simple to solve. They both worried for the other person, and how their roles within their relationships had changed and the difficulty that existed in adjusting to the new roles:

M:...There is a bit of a tightrope to walk I feel from my perspective, to be there and help you know, put things in place, and Fionn has a problem with the phone so I might say to Fionn you've got a text or somebody has texted you or somebody emailed you or for example...and there is a fine line between that and Fionn's privacy, you know, and that's kind of something that I'm very aware of in terms of being there to, I'm not Fionn's helper or assistant or PA, like I'm his wife, his partner...I don't want to end up doing things that Fionn can do himself [Fionn: yes, yes] or speaking for him, you know, at the same time being aware you need me or want me to speak for you.

F: Yes, yes.

M: So that's a kind of a fine line.

F: I think Maeve has an awful lot of work to do like, because she has to do her day work and then she has, you know, then she comes here when she comes home there is a lot of stuff for her to do as well, that I can't do you know, and that's [trails off].

Fionn was recognising the extra responsibilities now carried by Maeve, and how his role has changed in that there were now things that he could no longer do. Maeve was very delicate in how she both analysed their new situation, and in how she approached it, in that she recognised and emphasised the boundaries that should exist, and that she was first and foremost his wife, not his helper.

Trying to live well in the moment was not always an easy task, and the fact that dementia is a neurodegenerative disease was never far away; nevertheless, Fionn and Maeve acknowledge the difficulties and upset the illness caused, and will cause in the future, while at the same time trying to live well. Maeve summed up this balancing act:

M: ...one of the thing that I took out of that meeting and the diagnosis was, you know, things are never going to be better, so, we need to make the most of, you know I mean, ok it was a shock, it was a shock and it has been a shock, and it keeps being a shock, you know, because it has the impact all the time...and then you kind of realise that, and this is a problem, that is a problem, and so the shock is there but on the other side, you know [Memory Clinic doctor] said to us, it is like if you have a heart condition and somebody might say am I going to die of this heart condition, and you say well probably eventually, you know but we don't know when so in the meantime, you know, so, somebody could say I have a heart condition so my life is over, and might live for another 20 years or 50 years, so, I think our outlook, and we've been helped in this by say [friend] and the people that we've met over the years as well, is that anything we can do we will do, you know.

Living well was at the forefront of their outlook, and as a couple who love and respect each other, they made the most of what they can:

M: I think once you know, on one hand you deal with the shock and on the other hand you think well you know, we love each other and, you know, want to make the best and the most and if we can stave it off and do what we can to keep both of us well, you know.

Maeve's mention of keeping both of them well showed that while it was Fionn who is ill, it was implicit in their relationship and in their understanding of their new roles post-diagnosis that

they both need each other to stay well in order for things to keep working. The role their friends and family have played in supporting them both through spending time with Fionn has gone a long way to preventing the stress that would come by being a sole caregiver with little or no support.

Fintan had taken the bull by the horns in terms of living well with dementia, and did not let any of it impede him in any way. He was still working, and was also involved in national campaigns highlighting dementia and raising awareness of the illness. After his diagnosis, he came up with a plan for how to deal with the illness:

F: ... what I came up with for myself and I kind of thought it through fairly carefully so I had a structure to it, I said I need to do three things simultaneously, I need to prepare for the probable, which is you address all the issues about, you know the boring stuff, powers of attorney, enduring power of attorney, you know your finances...the other thing you then do is you work for the possible...which was do all those things which are seen to be of potential benefit, so, you know I immediately addressed diet, that is a big thing...and then the last thing was, the last element was that I realised I have to do was hope, and, I kind of realised initially that I was sitting there hoping to hope, and then I realised actually that's not, you just decide to hope, so I sort of got my head around that, because I would be, you know, I would be very much sort of a realist [laughs] you know I would tend not to be, I don't have the sort of you know dream it and it will happen...I don't believe in that sort of stuff so I had to kind of make myself see it as being something very concrete.

Here, Fintan outlined the three things which have enabled him to live well – prepare for the probable, work for the possible, and hope. Preparing for the probable was something that other participants had also done in terms of for example organising their will, or their advanced care plans. Working for the possible was something he felt very warmly about, having adopted a paleo diet to help his body work as well as possible, and embarking on a new exercise routine, among other things. His final step, hope, was not something that came naturally to him, as he explained; a realist, far removed from any dreamy notion of you can achieve anything if you want it enough, hope was a paradox. Nevertheless, he had reached a point where he felt that he would simply decide to hope – decide to hope that he can live well for as long as possible, even with an illness like YOD.

For his work, he had continued as previously with only very slight changes:

F: ...so what I'm doing now I suppose I'm working as I had worked before, but I'm tending to put in place, like I have an assistant when I'm doing the job here ... and I sort of, if you like I upgraded my assistant a little bit you know, I got someone a little bit more experienced, and I said you need to keep an eye and just watch and see if I am missing stuff and you need to tell me, and you know, all of that, but it has worked out fine and there actually hasn't been any need for them to draw anything to my attention, it's been fine...so, I'm if you like underpinning my work with a little bit of a sort of safety monitoring system, and all of that seems doable

The way Fintan had organised his work situation was an excellent example of how a person with YOD could still remain in employment with a modicum of reorganisation. Through recognising areas where he might fall short, and creating what he calls a 'monitoring system', he had made sure that he could continue working, and that the work could continue to be done without issues.

Fintan was very open with his diagnosis and it had not caused him any problems, however he acknowledged that this may not always be the case for all persons:

F: I suppose it simply, it underlies the reality of the situation if there is a job or work to be done that people are a little bit taken aback and surprised that I am being public, but that's only showing you well that's why I have to do this because it shouldn't be a problem, it shouldn't be a surprise [laughs] you know but it is and people are a bit taken aback, but certainly it may well be the case that I am lucky in the industry that I work in, you know people are used to mavericks and eccentrics and people being different and you know so there is much more tolerance, there is more tolerance for people being a bit more individual and themselves, so that's maybe a little bit easier, and certainly you know in the short period of time now that I have been public about it I'm certainly not finding any difficulty with people at work, they've kind of accepted and they are kind of saying oh ok, you know, if you are comfortable that's ok, you know.

As Fintan worked in the creative arts, he was surrounded by a more tolerant and understanding community; not everyone is that lucky and he acknowledged that fact. However, his openness about his diagnosis still challenges convention, and was a hugely important step towards confronting stigma and preconceived notions about people with YOD.

Together with his wife, Fintan was facing the reality of the diagnosis and they had both put safeguards for the future in place, in terms of supporting each other and being realistic of what will happen. At the same time, they had not lost sight of the importance of living in the present and not succumbing to disaster thinking:

F: [my wife is] frightened to a degree as to what it might mean in the future, I think she's possibly not quite as optimistic as I am, I tend to be you know prone to optimism rather than pessimism, and I regard myself as, I mean I still regard myself as a like an incredibly lucky person...I've have a lot of you know very particular good luck in my life, and this is a piece of bad luck, I mean I'm not in any way running away from or denying that, but you know that's all it is really...

Fintan was highly conscious of the increasing responsibility facing his wife when his illness reached a stage where he had limited awareness. His wife was preparing for the time when she would need to rely on the people around her:

F: [my wife] is very good at acknowledging and making, acknowledging the need for and making preparation for support, so she is you know she's already identifying if you like the key friends, you know, of, she has many friends but she is identifying the people who she knows will be really helpful and supportive and will be comfortable to be helpful and supportive...she's making, building those relationships and talking to people and she has a lot of good people around her.

Through continuing to work, exercising, eating well, planning ahead but living in the now, and minding his health, Fintan was showing a way of living well with YOD which was very different from the prevailing attitudes towards YOD. He was aware that by doing so, in combination with his openness and advocacy work, he was challenging the general discourse of doom around dementia, and lifting the silence and the stigma that is in the public perception. While factors such as family and community support, resources and personality have played a part in Fintan's experiences, and are not necessarily possible to recreate in all situations, his was nevertheless an example showing that life with YOD can still contain hope, and can still have goodness in it:

F: ...what I'd like to address is that very much more broad common communication, to not just people who have to deal with AD but just the entire population and say look, can we all just have an understanding of this that's appropriate, and you would hope that if that was possible, if that was helped, that then it makes it easier for anyone

who is impacted to make access to help and assistance [to deal with the illness] you know because it is not whispers and secrets and you don't speak of, so I'm just coming at it from that simple point of view, and I do think that if there was an improvement in that broad public perception it will inevitably filter down to impact beneficially on people who are dealing with the disease, that's what I'd hope to be the case, so.

Here Fintan was pointing out that the public perception of dementia affects the persons living with YOD; by accessing help and receiving assistance, as he had, life can be much easier for a person with YOD, and the stigma and 'whispers and secrets' that he mentions are all obstacles towards the openness needed to get some help and support, at least from a person's own family and social circle. If the public understanding was more appropriate, based on real experiences rather than horror stories, this would ultimately benefit those with YOD and help them live well.

Another participant whose lived experience of dementia was at odds with the prevailing social construction of dementia was Noírín. Noírín spoke at length about the different steps she has learnt to use to take control of her life, and that help her continue to live an independent life with dementia. By having these tools, she has been able to continue her lifetime habit of deep involvement in social and community issues; these have now turned into campaigning for awareness of dementia, and the rights of people with dementia on high levels.

She described the difficulties she still faces with mundane, day-to-day issues because of her dementia, and how it can be a source of problems and feelings of personal failure; however, once given the tools to deal with them, the mountain does not seem so insurmountable. The following account exemplifies this:

N: ...you just become absent-minded and those things maybe it is only for seconds you do it, but then you know you get so upset and then you lose it, because you realise oh God you know, I left the freezer door open one night, you know a thousand euro later, you know, I blew the whole fridge so, so there's stuff like that that you... you have to learn to live with that yourself, you have to learn how did I do this, why did I let it happen [emphasis], you know, and, so, you know you have your strategies, you are going to make mistakes but at least if you have some strategies so when that happened, I had to gather myself together and re-start again the next day and check my boxes, you know, check my list and I write lists and lists and lists and lists, I'm constantly writing stuff down that I have to do or people I have to call or, at this stage I've written volumes [laughs] but I have things to do today, you have to do it, and you

are going to make mistakes, but they are not as, they're not as great as you would have thought in the beginning, and so if we get the support to deal with all of that, at an early stage.

Noirín was not in any way pretending that mistakes do not happen, or that life is magically back to normal once you get tools and strategies for living with dementia; life with YOD was still hard, and mistakes continue to happen. But, as she pointed out, the tools and strategies for living well crucially help the person to evaluate the situation, and start again.

Noirín's involvement with a national level organisation helped her to find the confidence and to embark on her fight for the rights of persons with dementia; her activism had become a part of her way of living well with dementia:

N: ...it was I suppose with the support of the [activism involvement] really helped me to get out of myself and get out of the house and to, what, started walking and getting out and being visible again, and people begin to understand, I hadn't travelled on my own, I had driven very little actually, for somebody who has driven all over America, England, Ireland, Wales, Scotland, you name it but I just, everything came, began slowly but surely go back to things that were familiar to me... but one of the things that I have done is I've travelled, I travel on my own now which I wouldn't have done in a million years without all the supports, all the supports in place, so again it is about educating [emphasising] Ryanair, Aer Lingus, any airline, it is about educating airport services in terms of look we don't need wheelchairs, they always want to put me in a wheelchair I say no, no, no, then you have to say to them look I'm not, I don't want a wheelchair I want to walk so now the latest thing I do is a put my bag in the chair [both laugh] and so I travel, I travel all over, you know I've travelled to Europe, I travel to America, I think that is really important, to do stuff like that because all this, you are educating all the time, you are educating people in how to deal with the illness

Travelling alone to North America is not something that would be part of the public image of dementia, young or old, and the importance of Noirín's individual actions as well as her visibility are clear to see.

As mentioned in Findings Chapter Five, Noirín was a strong proponent of cognitive rehabilitation. Following her diagnosis, she eventually, after much searching, was able to access cognitive rehabilitation, which she saw as a key to being able to live well, and to be able to use the various tools for practical day-to-day things:

N: ...so she [cognitive therapist] did some cognitive rehabilitation with me and that really helped me to, do things I've gone back using a diary again I hadn't used a diary for so long, and putting some strategies in place here in the house, and just learning to cope again with different situations and I think that was just marvellous, for me, I mean that was it, that was the beginning of help for me and a road to recovery.

While Noírin manages her life with dementia very successfully to an outside observer, she does not shy away from sharing how difficult it can be, and that every day brings challenges, and some days are harder than others. These hard days, however, can be made easier with support, and if these supports were put in place in a timely and adequate fashion, it would make the process easier from the beginning. This is one of Noírin's core messages; while not a complete panacea, putting supports in place in a timely and accessible fashion makes a huge difference in the lives of those with YOD:

N: ...every day isn't a great day, there are some very sad days, there are days that I, you know, find difficult to cope like the last few days you know, any change in routine in your life is difficult, with, obviously you concentrate on one thing you lose something else, so, but, at the same time, you know that you'll get through it, you know that if you take a small chunk at a time, instead of taking the whole lot together, that you'll manage, you know, and there is always somebody to talk to, you know I can ring one of the [activism organisation or contacts], and if I am struggling I can go to my GP who's fantastic, I am lucky I have a great loving and supportive family, so, and but I didn't look for their help initially, I didn't talk to them, I didn't want them to know, and, and so therefore that's what happens to a lot of people, you know, as I've now discovered with the [activism committee], the more we meet new people the transition from having a very active great life to having a hell of a life, just a hell, going into hell, a hellhole, it is just, that absolute, and that's why I think for me I think I have to honestly say, that if cognitive rehabilitation has been there in the beginning when I was diagnosed, a very minimal amount, I'm not asking the state to pay vast amounts of money, I'm saying a minimal amount to just get you started, just to get you on, your diary, to get some strategies.

Cognitive rehabilitation is a relatively simple yet effective intervention, and had proven to be very important for Noírin. The difficult period that Noírin went through after her diagnosis comes to mind when she speaks of people 'going into hell' after their diagnosis; she wants to

use her experience to make sure that practical supports that make a big difference should be available from the beginning.

Being diagnosed with dementia while under 65 years of age has brought particular challenges, and Noírin outlined how these challenges are sometimes not even realised by organisations working for persons with dementia, representation of the illness being one of them. This again shows the importance of her activism work, and the voice afforded to persons with YOD by her work:

N: one of the things that I have talked to [national dementia organising] about and it's something that we've dealt with to some extent, we are not all old grey looking, looking very old, and every photograph that you'd look at, if you look back there are all older people, and I mean old as in 80 to 90, and anyway they are models in most of the cases, you know so, we're trying to change that, we are not all old and infirm, there is, yes there are older people and infirm and yes there are situations where we need to have those photographs, of course, but you shouldn't, that is not the total full face of dementia...yes I'm 65 now when I was 55 you know, is that the kind of photograph I wanted of myself, and that's another thing that needs to be changed.

Noírin's grief at her diagnosis and the dark days that followed with struggling to find out about services and supports and finding nothing, in combination with the stigma surrounding dementia, were all very challenging. However, by using the voice afforded her from her experiences and her awareness-raising and activism work, she points out that while life with dementia is difficult, it is still possible to live with it and still contribute to society.

N: ...believe me it is not easy to come out and tell the world you have an illness you know so, especially because of the stigma attached to it, so I think all that whole, that whole thing, that myth about it is changing...I think we have to make the change, so hopefully, hopefully our work is going to pay off and others will not have to suffer, and I mean, and I don't feel now, you know people think I'm suffering and I say to them I'm struggling I'm not suffering, yes I'm struggling with my illness but certainly I'm not suffering with it

The distinction between struggling with YOD but not suffering is a key point. The picture painted of those with YOD as passive victims to a disease which is considered so awful that those with it are even afraid to tell people that they have it, is being challenged by the lived

experience which can say that while it is difficult, and while life with YOD is a struggle, it is not untold endless suffering, and can still have quality and value.

Similarly to Noírín, Orlaith described how difficult life with dementia can be, and how it had changed everything for her, from practical things like cooking to not being able to enjoy things as much, such as reading:

O: ...I can't follow recipes anymore, sequencing like that is just a nightmare, I can do it but it is a nightmare, you have to go back to step one every time to make sure there is nothing lost, I find I get very overwhelmed if two or three things are coming at me at the one time, so I need to be organised and, you know, I need total organisation, I need, you know, I need my diaries, you know my son is doing his, his [exams] at the moment and it is constantly checking, what is he doing tomorrow, because I don't want him feeling well I'm just not interested, but like it just escapes me what he's doing tomorrow or what he's done today and I'm constantly reading and checking, my reading, you know I would have gone through a book a week I loved reading, I loved learning, that's all gone, absolutely completely, if I read now, tomorrow night I actually have to re-read several pages to catch up where I was, sometimes I find it so frustrating, if there's a twist of a plot in the book, the book goes down and that's it...

Orlaith was channelling a lot of her frustration at lack of services and support into working to change this, and secure a better overall structure for persons with dementia, both at diagnosis/disclosure and for living with dementia. Orlaith in particular identified dementia advisors as a source of support that should be extended:

O: ...I know it is a huge thing and I know it is very early stages of kind of looking at the help for early onset because I think it is basically being sure while [you have no major cognitive impairment] you're ok, but actually I don't agree with that at all, I think there are facilities needed to help talk you through, I think the dementia advisors, there are only seven in the country, I think each person should have somebody assigned to them from the get go, and they come in to your house, as you are able, and they figure out well what difficulties are you having, what difficulties are you having, so let's put practical steps into place, and work with them, it might be a few hours and it might be over a few times over a few weeks, but I think early onset AD is very, very different care is needed than somebody who is elderly, I think they are polar opposites, you know.

The differences between YOD and LOD that Orlaith refers to includes the fact that, as she had mentioned above, she for example was worried that she was not keeping up with her son's college exams, and made a special effort to put this into her diary. Her responsibilities as a person with young adult children, still very much reliant on her, were very different from those of an older person. Nevertheless, it is worth noting that care and support services for older persons with dementia, while more extensive than those for YOD, are very often still found wanting.

Having always been an active volunteer in a wide range of fields, and now being involved in awareness raising and being the face of a nationwide campaign was something Orlaith was glad to do. Mentioning Gandhi's famous quote "be the change you want to see in the world", she summarised how her campaigning and activism work is both a calling, as well as a motivator to keep going:

O: ...and I can, for me I think, if I was to sit with that every day and have no purpose or no goals, I think I'd just give up, let it on, and therefore if you are going to feel that way you are going to be that way...so I just feel while one side of my volunteer work and all that is gone, and it has to go, I just feel getting involved in the likes of this and being a service to other people is something that I can focus on and keep a little bit active and kind of moving forward so...

Niamh stood out among the participants in terms of living well with dementia, in that she saw mainly positives in her new life, and did not really miss her life prior to diagnosis. Like a number of the other participants, she was also active in awareness-raising and campaigning, albeit not to the same extent as Noírin, Orlaith and Fintan. She enjoyed the changes in her life that occurred as a result of her diagnosis, and viewed life with YOD as a good experience.

N: well I suppose, the major part of the effect [of diagnosis] I suppose was being able to meet my friends, you know for golf, sports, whatever, and then other people for cafe Costa and all that kind of stuff you know, and you know all that kind of stuff was just lovely over the summer, really, you know, I just, it was just the best time ever in my entire life, you know, to get out to [beach town] and stay with friends down there and go swimming and you know, it was just, it was real idyllic, the whole last summer and I am hoping it will be the same now this year...that was a major plus to be with friends again, because I really only had weekends to do things and get things done and all of that sort of thing so yes that was a major thing.

Niamh had been open about her diagnosis with family, friends and her wider community, and with the increased amount of leisure time that came from not working she was able to spend all her time only doing things she enjoyed. Niamh employed strategies to help her with her memory and to organise things, as the lack of a routine from work meant that she was starting to become forgetful:

I: And do you have any kind of routines to help you, I see the white board there...

N: Yes, yes, it is good, that is great, and I have a smaller one as well because I have been forgetting some of the times my, my, you see I suppose when, when I stopped working I hadn't, I didn't get a routine, I didn't do a routine I just did golf and tennis and things like that, so I suppose I started to forget some things and relax too much, and then I, so I have the second little board, a bit bigger than that, and, a bit wider so to speak, so I use that one for tennis and those kind of commitments so that I try not to forget, because I have forgotten and, you know it is not nice when there is only three people in a four-man team [laughs].

Her illness meant that Niamh's driving had been restricted. She lived in a small city, and had been told that she should not drive further than locally, around roads already familiar to her. This frustrated her, but it was nearly the only time she was negative about her dementia throughout the interview:

N: ...well I suppose, you know, I don't like being confined, you know somebody telling me to be, that I am confined, you know from here to there sort of thing, that irks me quite a bit, you know in terms of the driving and that kind of thing, you know, and I mean I go to [rural town] for my holidays you know and that's going to be a bit of a trek, you know, trying to go on a bus you know, to bring your gear with you and all that sort of stuff, you know, that kind of stuff will be a bit of a trek, so I'm, I don't like all that stuff, yes, that's the worst part of it I suppose, you know but, then again you know, I have a very comfortable, you know, lifestyle with everybody is around, you know, so.

A single woman, Niamh came across as very independent, and had previously lived in the Middle East and Asia for over ten years. Being confined to her small city was obviously a challenge for her, but one that she was facing head-on by deciding to take the bus to the other side of the country for her holidays.

While she had a good level of insight, Niamh had prepared a written statement about her dementia before the interview in case she left anything out, and she wanted this to be part of the interview. We read the statement together for the benefit of the Dictaphone, and the following exchange exemplifies Niamh's attitude to her illness and how to live well with it.

I: And sailing, sailing, is that what it says, "I found sailing but golf was a big draw, cinema, meals out, meet friends, acquiring Alzheimer's was the greatest thing that ever happened".

N: It was really at that time, you know, it was for me.

I: Yes, "suddenly I had all the time, tennis, golf, swimming, when I was working there was little time for friends, I drove up and down to [small city] to work, tiring, I'm in the gym 5 or 6 six days for my neurons, making new friends there, cold at the moment, avoiding the bike".

Saying that getting Alzheimer's Disease was the best thing that ever happened was a truly remarkable assertion. The statement continued to outline the sports Niamh was involved with, and the people she regularly meets, either for tennis or golf or socialising, and how much she feels in debt to them for the kindness they have shown her and how much she enjoys their time together. While I could of course only take Niamh's assertions at face value, it was difficult not to wonder if the positive view was only one side of her experience, and if there was another, less positive side that she had chosen not to show. Nevertheless, Niamh continued to explain how her quality of life had improved, for example how her dementia has enabled her to spend more time with her mother:

N: that has been the, the best thing ever, you know, because my mother, I was always working and I was always, you know, if I could meet somebody afterwards I was gone, you know, and then one day I realised my mother is probably very lonely as well, you know, and that kind of thing, you know, so it's worked out really well.

Niamh had a good support structure around her, with her sister-in-law helping her with anything bureaucratic or medical-related if she needed it. Her optimism meant that most of the time, she enjoyed what she saw as new-found freedom instead of mourning the change to her life that dementia had brought.

6.5 Discussion and concluding thoughts

This final Findings chapter has looked at data related to the personal sphere of life of the participants. The experiences of work, in relation to ceasing employment because of the YOD, or in one case, successfully continuing to work, was discussed in the first part. The second part reviewed the findings around the area of children, and the participants' concerns and experiences of navigating their YOD in relation to their children. The final part looked at living well with dementia, where the various strategies and outlooks employed by some participants allowed them to not only live, but live well with dementia.

Haase (2005) found in his study of YOD in Ireland that of 61 participants, only one was still in employment. The main reason the other participants had left employment was that their YOD meant that they were not able to fulfil their work obligation. The difficulties faced by the participants, richly described by for example Fionn's example of not being able to collate pieces of paper, all point to major obstacles created by the YOD. In the first findings chapter (Chapter Four), Micheál described checking the file of a client before their arrival so he could remember who they were and why they were there. This type of coping strategy is one of a number that Roach (2017), Ritchie and colleagues (2015) and Chaplin and Davidson (2016) describe as a way in which employment for a person with YOD could be continued. The increased anxiety and pressure build-up from work issues can in turn make the pressure on the person even greater, causing anguish and affecting already strained abilities (Ritchie et al., 2015). This seems to have been the case with both Niamh, who described getting regular 'bollockings' from her manager, and for Finn, who felt a lot of anxiety around his work.

It is difficult to not ascribe many of the issues around employment that the participants experienced to a lack of openness, which in turn relates to the high level of stigma surrounding dementia. In Chaplin and Davidson's study, the strategies and tools used by persons with YOD to cope in work were hidden from management and colleagues (Chaplin & Davidson, 2016). If they had been able to be used openly, and if there had been policies or strategies around how to deal with dementia in the workplace, as outlined by Roach (2017), some of the participants in this study may have been able to remain in work longer. Niamh, who worked for a major national bank, may have been able to be better supported, or maybe even be offered a different type of position within the bank, rather than ceasing employment. Micheál and Fionn's situations were slightly different as they were not employed in a large company, however their reticence about the symptoms they were experiencing meant that the performance issues continued, as did the stress their work issues caused them. For example, the problems Micheál encountered with being reported to the professional body for his

profession, and then not being able to close out many outstanding issues when he was leaving his company as the regulatory office would not deal with his correspondence, may have been avoided somewhat if he had been able to be more open about his illness.

Sean's experience was slightly different – he was not in employment at the time of his diagnosis, however the YOD and the issues he was experiencing meant that he did not look for a new job. While his previous work as a caretaker had been quite solitary, he nevertheless missed being able to contribute, and having a purpose with his day. His loss of work combined with the fact that they had only told very few people about his diagnosis, meant that Sean was spending a lot of time at home. This in turn put increased pressure on Aisling, who was Sean's main support person as well as providing the only income to the family. Working as a care assistant, Aisling's work was tiring and she often worked nights, which causes extra pressure. Again, it is difficult not to see the undercurrent of stigma as a cause to many of the issues experienced by Sean and Aisling. As very few people knew about the diagnosis, there was only a very small pool of people to provide help, and as those include their children who themselves were working or in education, virtually all responsibility fell on Aisling. It is of course also important to highlight the role of the provision of services here; suitable and accessible services for person with YOD would significantly lessen the pressure on both Sean and Aisling.

Tadgh's experiences in relation to work were particularly interesting, as it was the one topic throughout the interview that animated him to a certain extent. His keenly felt loss of work also seemed to be connected to having something meaningful to do; throughout the interview, Caoimhe was continuously referring to him going out for walks multiple times a day, or wanting to come to work with her, or always asking what they were doing for the day. This again echoes the findings of Chaplin and Davidson (2016), who outlined how loss of employment does not only have economic consequences, but also affects the sense of self-worth, the identity of the person, and brings with it a loss of the daily social interactions which come with working, as well as a meaningful occupation. The issues of a lack of services again come into play here, as Tadgh seems to need a lot of physical and mental stimulation throughout the day. Suitable, age-specific services would make a big difference for both Tadgh and Caoimhe.

Employment is one of the main ways in which YOD differs from LOD. The experiences in this study of the struggle participants had with employment, the treatments they received because of it, and the anxiety related to it, was a major finding and really highlights the unique

pressure that YOD puts on a person compared to LOD. Another major finding in this study which is unique to the experiences of YOD pertained to the children of the person with YOD. There seemed to be a dearth of research specifically on this topic; most of the literature concerning children related to the children or the parent/caregiver who was not ill. By giving a voice to the person with YOD, this study provides an insight into the thoughts of the person with dementia and their feelings, concerns and experiences around their children and the illness. The data from the participants strongly suggests that the participants, not surprisingly, worried about how the illness affected their children, at times excessively so. There were also concerns from some participants as to how their children were experiencing their openness and often public persona in relation to their illness, which was a fairly niche and unique experience.

The data powerfully portrayed the parents' worry for their children, their wish to protect them, and efforts to prepare them for what is to come. Orlaith was probably the participant who spoke most about her children, and who expressed most worry about them. As both her sons had experienced problems of their own, and one had autism, her concern was understandable; also, the fact that she was parenting alone, with her own extended family living in another part of the country, exacerbated the problem. Orlaith's concerns for her children and how they would cope when she became very sick, or when she died, were communicated very openly throughout her interview, and it was an issue which weighed heavily on her. She went to great lengths to keep up with her children's day-to-day life, and also made sure to be open with her children about her situation. While she had a very open and loving relationship with her children, her worries seemed at times to overshadow her own concerns, and were projected far into the future. Her children were very proud and supportive of Orlaith and the advocacy work that she was doing, however it is difficult to know if they realised the extent to which she worried and mourned the fact that at some point she would no longer be able to fulfil her parental role of guiding them as they navigated into adulthood.

Tadgh and Caoimhe's three sons featured regularly throughout their interview, as they were still quite young, with the youngest in his mid-teens. The three boys had all exhibited different reactions to Tadgh's illness, with the oldest expressing anger, the youngest missing 'old dad', and the middle son supporting and helping Caoimhe. Aslett and colleagues (2019) found that children of a parent with YOD might feel worry or fear for the healthy parent, and try to support them as much as possible, sometimes at the expense of their own stress levels. Caoimhe, however, seemed aware of the difficulties facing the boys, and was concerned that none of the boys had accepted offers of counselling, which she herself had accepted. The fact

that she could not shield the children from the negatives of the illness, or adequately explain to them why it was not Tadgh that was to blame, but the FTD, was a very difficult situation for them.

The anecdote of the incident by the pool in Portugal showed not only the unsettling and troubling experiences that children may be faced with and how difficult this must have been for their younger son, but Caoimhe's powerful comment that she almost hates who he has become showed the level of contradictory emotion that can exist. By stating that *"there is still parts of me that sometimes hates the person he is almost, and I, I mean, I try and never ever show him that, but that's huge for me"* Caoimhe very openly described her conflicting feelings towards Tadgh caused by the behavioural issues present in FTD. An important part of understanding Caoimhe and her family's experiences of Tadgh's illness can be found in the high level of behavioural issues in FTD, which negatively affect both the physical and mental health of the caregiver (Bakker et al. 2010); also the degree to which having a parent with YOD is fundamentally different even from other serious illnesses like cancer or chronic conditions is easy to grasp when viewing their situation (Johannessen et al. 2016a).

In her comment about the Portugal incident, Caoimhe also referred to Tadgh's age, saying *"if he was older, you'd sort of excuse it like"*. This comment can be interpreted along the lines of what Tolhurst and colleagues refers to as the non-normative nature of YOD (Tolhurst et al., 2014); an outsider would see a young, regular person and therefore not expect any kind of unusual or different behaviour. If Tadgh was old, or if there was a physical signifier of his YOD, Caoimhe reasoned that perhaps his day-to-day irregular or unorthodox behaviour may not come as such a shock to people, and even she would excuse it more. She nevertheless put great effort into trying to do what she could for the children and Tadgh to continue to have a relationship as far as possible, encouraging the children to reach out to him and stating that she does not want them to regret anything.

Like Tadgh and Caoimhe's children, Sean and Aisling's four children all reacted differently, from excessive grief to not crying even once. The fact that Sean was spending a lot of time at home meant that he was becoming frustrated even with the children, a situation that Aisling found upsetting but powerless to prevent. Much like Caoimhe, she was bridging the gap between the children and Sean, and did this while working and being the main support person for Sean. Some of the participants in Haase's study had not experienced any difference in their relationship with their children, as their partner played the main role as support person and kept all aspects of the relationships at an even keel (Haase, 2005); this could be said about the

situation for Sean and Aisling, where Aisling is supporting Sean on her own while also looking after their children and supporting them through difficult times.

Yet again, it is important to note that the lack of services in Ireland plays a role in the difficulties experienced. Services have a role to play even in relation to children, with Mayrhofer and colleagues (2018) showing that children of persons with YOD tend to feel overlooked and that their needs are not met, but that meeting other children in the same situation and getting both recognition and support, is very helpful. If there existed a network of family and/or children's support groups across the country that was easily accessible, perhaps children like for example Tadhg and Caoimhe's children who, for whatever reason, refused counselling might decide to come along, as this may not feel so serious or intimate.

One example of where there was no overt amount of anxiety or worry around children was that of Fintan. While acknowledging that it had been difficult for his children, Fintan had tried to instead explain to them that there was no need to be worried about the immediate future, and he did not seem to be anticipating negative or unhealthy concerns about the future either. While very realistic, explaining to them that his illness, and him being public about it, is actually not something to be afraid of, he had also ensured that his children had other significant adults present in their lives, and his children had been given a number of good tools to deal with the situation. Like a lot of the data provided by Fintan, this example of his approach of dealing with his children was based on openness and a refusal to submit to any type of stigma, and a firm stubbornness to keep living his life as normally as possible. This major finding of living well with YOD was the final finding reported in this chapter, and was an unanticipated but important outcome of the study.

As the participants detailed their experiences, issues around making the best of the situation and being proactive and creating a new reality, a scenario adapted to life with YOD but still with a good quality of life, showed up repeatedly. This was evident in a number of areas, such as for example the lack of meaningful activities for the person with YOD. As all but one of the participants were not working, the days were at times difficult to fill and issues around capacity at times meant that the person with YOD could not pursue a hobby or similar on their own. Here, Fionn and Maeve benefitted greatly from their openness about Fionn's diagnosis, as friends and family were aware of his situation and came by to spend time with him on a weekly basis. They had also joined a walking club, and gotten a dog – all to ensure they were kept active.

This emphasis on keeping active and staying involved was made possible by their openness, both with their surroundings and with each other. Maeve was conscious of not invading Fionn's privacy when she helped him with tasks or was in contact with his friends, and there was a sense of the importance of their spousal identity being very strong. While obviously having taken on numerous responsibilities, their relationship as spouses as opposed to carer/person with YOD was still retained and this came across as very important for them. Wrapped in this was also a hope that they could keep the YOD at bay and continue to live their lives together, for as long as possible. The lack of services for persons with YOD probably meant that carer/person with YOD identity was stronger than they perhaps would have liked, but they were nevertheless making the best of it.

Niamh was an extreme case of living well – an outlier even when compared to other participants who were living well with YOD. She saw virtually only positives with her diagnosis, explaining how before her life was a rush to get to and from work and then try to squeeze in friends and activities at weekends. Now, after her diagnosis and after having to stop working, she had all the time she could want to pursue her favourite sports, including golf and tennis, which she did voraciously. She also spent a lot of time with friends and family and expressed deep gratitude to the friends and neighbours who were keeping an eye out for her and that she socialised with. Part of the activism group, albeit not as visible or active as some of the other participants, she also used tools such as white boards and even expressed an interest to attend an access course in IT to refresh her memory so she could pay bills and related things online. This level of motivation and agency kept her going and kept her active and motivated.

While her embrace of her diagnosis and her enthusiasm for her new life was evident, this was the part of the experience that Niamh chose to focus on, and may not have divulged her less positive feelings around her YOD. When re-telling the story of how she visited the doctor at her (former) place of work, she outlined how *"I suppose I cried and I did all kinds of things you know [laughs] at that point...because it was kind of emotional, you know, having to sort of say these things over and over I suppose to some degree"*. This indicates that Niamh did find at least the diagnostic part of the experience of YOD troubling at times, and that it has not all been a straightforward experience. Nevertheless, her current approach to her situation, although extremely atypical, shows a great capacity to adjust to a new life scenario.

Niamh had always been very independent, and this seemed to work in her favour after diagnosis, with her showing no fear in relation to her new situation, and embracing tools to facilitate her life, such as the whiteboards. The use of strategies and tools for coping with daily

life was an important part of living well with YOD, and was a great support for a number of participants. For Noírín, being able to access cognitive rehabilitation was the beginning of what she described as her “*road to recovery*”. While she was very open about still having what she calls sad days, and could be upset at times about her situation, having the tools to create a routine and a way of handling or working around some of the obstacles created by the YOD had made an enormous difference for her. It had restored her independence, enabled her to continue her active lifestyle where she was involved in committees and organisations, and has helped her to be an active advocate for persons with YOD on high levels.

Fintan was living well with dementia in more than one way. Still in employment, he embodied the way in which a person with YOD could easily be accommodated to stay working, and how these accommodations could change or increase as needs shifted. One of the main ways in which Fintan had created a situation whereby he was living well with YOD were his three steps of coping. After his diagnosis, Fintan had read extensively about dementia and had changed his diet and adopted a new exercise routine to maximise the benefits of his health and to the benefit of his brain health. His investment in his physical health was a way in which to stay active, and to have some agency in doing something to help his body; a way to maintain some form of control over the situation.

Fintan’s final step of coping, and one which was echoed by other participants in different ways, was that of having hope. Describing how he was ‘hoping to hope’, he decided that it was not something that you wait for, but something you just do – being a very pragmatic person, and knowing the realities of dementia from seeing his father go through the illness, Fintan knew that the prognosis of YOD was unlikely to change. However, he still persisted in doing what he could to stave off the illness, and to continue to live well while he could, and hoping to prolong that as much as possible. This hope was crucial, and also translated into his advocacy work, where he spoke passionately and at length about the stigma of dementia, and the importance to challenge the inappropriate and inaccurate reactions to the illness. Harris and Keady referred to the negative ‘label’ of dementia being so powerful that no sense of hope or continuity of everyday roles was possible (2009); Fintan had grasped this in his work, and focused on challenging this in all and any ways which he could. Like a number of the participants in this study, by living well with YOD he provided the most powerful and visual challenge possible.

CHAPTER SEVEN – CONCLUSION

7.1 Introduction

The research for this thesis was conducted with the aim of investigating the experiences of people in Ireland who were diagnosed with YOD. The findings from the interviews carried out include unclear pathways to care, poor disclosure practices, limited access to social services, high level of stigma, as well as how the illness affected the participants' personal sphere of life in relation to employment, children, and living well with YOD.

As outlined in Findings chapters I, II and III, the individual experiences of the participants painted a picture of struggle, sadness and difficulty but also of hope, ability, positivity, and resilience. While some participants were struggling with the diagnosis and their life with YOD, there was also a thread that ran throughout the interviews of employing tactics and strategies to counteract the struggles and live well with YOD. This does not mean that the participants were not experiencing difficulties, or struggling with their daily life, or mourning the life they had – they were still experiencing that, and the inexorable trajectory of the illness was always implicit in the interviews, if not mentioned head-on. However, the tough reality of living with dementia does not mean that one cannot still live well, albeit in a different way to what 'living well' may have constituted pre-diagnosis. The participants showed this in abundance – sadness and difficulties can exist in parallel with hope, ability, and quality of life.

In this final chapter, I will outline the original contribution of the thesis to knowledge. This will be followed by a summary and analysis of three main areas, informed by the data from the participant interviews, that contain the main recommendations resulting from the study. I will then discuss what I learnt while writing this thesis, as well as the limitations of the study. Finally, some personal concluding thoughts finish the chapter.

7.2 Original contribution of thesis

To the best of my knowledge, only two major pieces of research have been carried out in relation to persons with YOD in Ireland, Trutz Haase's *Early Onset Dementia - The Needs of Younger People in Ireland* in 2005 and the 2020 report published by the National Dementia Office and authored by Fox and colleagues, *Young Onset Dementia: A Review of Diagnostic and Post-Diagnostic Processes and Pathways*. Described in the final section of Chapter Two: Literature review, these pieces have provided much-needed data on YOD in Ireland, and

outlined the shortcomings of provisions for this group, as well as incorporated the voices of the persons with YOD and their families.

This thesis adds further to the information and knowledge contained in these two pieces by contributing a new angle and an in-depth understanding and analysis of the individual experiences of the persons with YOD in Ireland. The exclusively qualitative nature of the thesis, and the focus on the individual experiences, as opposed to also including for example policy makers or other stakeholders, meant that the focus rested solely on the individual with YOD and could delve deeply into the participants' personal experiences. The focus on the individual and their experiences, even in interviews where the spouse or partner was present, was in line with the constructivist and phenomenological angle of the thesis: this is an important underpinning as it means that there was a continuous return to transcripts and the spoken word of the participants in order to re-interpret and analyse the data.

Both the hermeneutic and idiographic aspects of IPA methodology helped to extract the in-depth insights that came from the interviews. The sharp focus on exploring the experiences of the individual allowed for the findings and analysis to describe and illustrate what these were in a greater way than had previously been done, and the richness of the data very much reflects this. Data which gives an in-depth insight as to how persons with YOD experience different parts of their illness, such as health care interactions or the provision of services and supports, are crucial if we are to understand on a deeper level what is needed, and why. In addition, the findings around the lived experience of YOD in terms of family life and living well are also a major contribution, as they outline more personal concerns and give a clear voice to the person with YOD. For example, the voices of the person with YOD in relation to their children, as opposed to the voice of the partner or the child, is not often heard in research, and is a significant contribution, as is that relating to the participants' experiences of issues around employment.

This thesis set out to explore the experiences of persons with YOD, to listen to them and to give voice to how they perceive life with YOD, and what experiences they have had and how they have been affected by them. By employing strictly qualitative in-depth research techniques, the nuances and complexities of life with YOD in Ireland could be heard, and this unique contribution is of great importance.

7.3 Future Research and Recommendations

7.3.1 Pathways to care and health service interactions

Research has shown that persons with YOD are more likely to face barriers to diagnosis, accessing information about YOD, get a large number of referrals, and often report that the medical profession do not understand their concerns (Novek et al., 2016; Van Vliet et al., 2011). This was also the case for the participants in this study. As was evident from the data, many participants experienced confusing and unclear pathways to diagnosis. The issue often began already with the GP, who tended to not even be aware of the possibility of YOD, and was often nonplussed in relation to the person's symptoms. The limited knowledge of GPs was sometimes mirrored by the specialists that the participants were referred to, with only three participants being referred straight to a Memory Clinic. The remaining seven were attending other specialist services, sometimes to no avail like Fionn attending a private psychiatrist, or Margaret who was poorly treated by the specialist. In the case of Tadgh, the geriatrician and stroke specialist that he was referred to did not know what to do with his diagnosis of FTD: however that did not stop him putting Tadgh on Aricept, a drug designed to slow down AD that has no relationship with FTD.

The limited knowledge or awareness of YOD from the medical professionals was a worrying finding. While many health care professionals do not expect to see dementia in a younger person, and tend to suspect psychosocial issues such as burnout or depression instead (Chaston, 2011; Van Vliet et al., 2013), the general lack of knowledge was still an issue for a number of participants in the study. Stigma also plays a part in the diagnostic uncertainty; while stigma and diagnostic nihilism are a well-established factor in delays of diagnosis for LOD (Cahill et al., 2006; Moore & Cahill, 2013), the situation for YOD is similar. Werner and colleagues found that healthcare professionals felt great discomfort working with persons with YOD, and both they and their colleagues reported disbelief that they would be able to cope with such an 'awful' disease (Werner et al., 2019). Such stigmatisation is highly troubling and its effect on both the health care professionals and the person with YOD is certain to be detrimental.

The participants that attended a Memory Clinic were generally happier with the disclosure process, with the exception of Orlaith, who was given her diagnosis in a car park. The poor disclosure procedures experienced by other participants were a contributor to their difficult post-diagnosis period. Orlaith felt patronised and confused by the conduct of the health care professionals who were supposedly giving her a diagnosis of YOD; instead of telling her in a

straight way with appropriate supports present, they spoke in circles and in euphemisms. For Bláthnaid, being given a diagnosis over the phone – twice – was terribly damaging, and left a deep mark on her. Much of poor disclosure behaviours can be explained by the issue of therapeutic nihilism (Fisk et al., 2007), and the power of the stigma of dementia has made this therapeutic nihilism nearly self-fulfilling. For example, GPs have reported a lack of knowledge as a barrier to diagnosis, however another barrier is also the perceived lack of supports and therapeutic nihilism (World Health Organisation, 2012); in other words, the therapeutic nihilism and the sense that nothing can be done is as present as the recognition that they actually do not know enough about the illness.

The confusion and uncertainty around where to turn and how to address what was happening created much instability and difficulty for the participants; the lack of effective or clear interventions even by specialists was also an issue. It is important to point out that not all participants had lacklustre GPs or uninterested specialists; for example, Fintan and Sean were both referred to a Memory Clinic immediately by their GP, and in Sean's case he was referred to two to speed up the process. However, it is in these cases that we can see how straightforward the referral process could be, and that the confusion and sense of being sent from doctor to doctor to no avail could be avoided. Also the Memory Clinics, with the exception of Orlaith's experience, generally conducted not only proper assessments but also delivered the diagnosis with great sensitivity and suitable supports in place. A clear pathway to diagnosis for person with YOD is urgently needed, including proper disclosure practices and a support structure and information for the period immediately after diagnosis. Having clear care pathways would create common standards, and involving those affected by YOD in designing services may address specific issues (Mayrhofer et al., 2018), and would be a necessity for the care pathway to be appropriate.

7.3.2 Supports and services

The difficulties that Margaret had experienced in getting a medical card were emblematic of the systemic issues relating to health care and social care services that affect the general population in Ireland, not only those with YOD. In addition to this, the other findings in relation to services in the study showed a major lack of most types of services, whether ongoing services such as suitable day care, or services of a more practical nature such as access to cognitive rehabilitation, or support services such as peer groups specifically for persons with YOD.

Noirín spoke eloquently about the need for specific services such as driving assessment, cognitive rehabilitation, and suitable day care. As has been discussed, services for persons with dementia are underdeveloped in Ireland (Cahill et al., 2012), and the situation for persons with YOD is even more dire, with very limited provision of services targeted specifically for this group continuously being raised as an issue (Fox et al., 2020; Haase, 2005; O'Shea & O'Reilly, 1999). Noirín mentioned the existence of hiking groups for persons with YOD in Scotland; Fionn and Maeve had joined a ramblers walking group, however Maeve always had to come along as Fionn would need some help with certain issues. A walking group specifically for persons with YOD would have been ideal for him, and it would also be a chance to meet others in similar situations. The distress Caoimhe described after leaving Tadhg at a dementia day service for older people every week was a strong example of the unsuitability of such an arrangement, but at the same time showed that the need for services was so strong that this was considered better than nothing at all.

Noirín outlined the need for a plan to be in place for the immediate period after diagnosis, which assessed the abilities of the person with YOD, provided cognitive rehabilitation, and linked the person with further services. Such a plan would help in the early days, and would also be tailored to each person's specific needs. The strong need for a full range of services for persons with YOD have been repeatedly highlighted over the last two decades and counting, with little to no progress. For example, Haase recommended the development of services such as day care specifically for those with YOD, as services for older people were fundamentally unsuitable; he made the point that older person's services are unsuitable not just for the person with YOD but also for staff, who may need to spend more time with the person with YOD than is possible due to the person's higher level of energy, physicality, and needs for stimulation (Haase, 2005). Similarly, Fox et al (2020) also highlight the need for a wide range specific services in Ireland for those with YOD.

Recommendations for an increase in services are reflecting the lack of services that have existed for a long time, and some services, such as social groups for person with YOD, would be a low cost and uncomplicated service to organise, with a potentially large and positive impact. While practical supports and ongoing services providing day centres or activities such as for example hillwalking would be of great benefit to the person with YOD, the effects would also be felt by the person's family, as they could encounter others in a similar situation. Also, a wider support structure could have a family-oriented angle and include the children of the person with YOD; the benefits to a child or very young adult of such support systems include

helping them establish themselves as individuals in their own rights, and continue with their own lives (Johannessen et al., 2016a).

Another area where the results from this study showed that supports were non-existent were in relation to continuing with employment. Fintan, the only participant still in employment, was able to keep working as his industry was open-minded, but mainly also because he was able to put in appropriate supports in the form of an assistant, who was able to make sure that all things work-related were still functioning. However, he was paying for this himself as he was self-employed, and he acknowledged that not everyone would be in a position to do so. A number of participants ceased employment when their symptoms began to interfere with their abilities; however, if diagnosis was quicker, or if places of employment had more supports that they were able to put in place to facilitate the person affected, this may not have been necessary.

One example that stands out was that of Niamh, who experienced poor and aggressive behaviour from her management in relation to her sudden lack of ability. Roach outlines a number of ways in which a person with YOD can be supported in the workplace, such as increasing supports, modifying activities or perhaps a new role; but the core of her argument is that the personhood and identity of the person can be maintained through support enabling them to continue to work in a meaningful way (Roach, 2017). While Niamh wryly commented that a bank worker who cannot count is not of much use, the very large national bank that she worked for could, if such a structure was in place, have facilitated her remaining as an employee in some form or another. Smaller companies that may struggle financially with providing supports for an employee with dementia could be facilitated through some form of state support – the point is that if persons with YOD were able to be accommodated in the workplace, much like persons with a physical disability, it is highly likely that more would be able to remain in employment.

The importance of services for persons with YOD is difficult to overstate, as the current virtual lack of services in Ireland is one of the main findings of this thesis. Because of the nature of YOD, it is necessary for services to be personalised as need will be different, partly because of the illness trajectory but also because those with YOD are more likely to have rarer subtypes of dementia (Hoppe 2019). Fox and colleagues (2020) highlight the need for there to be a clear pathway between diagnostic and post-diagnostic services for persons with YOD, and that the two should be integrated and be responsive to the preferences and changing needs of the person, and their family. This point is crucial; without the development of personalised

pathways that take into account all the needs of the person with YOD, the person's autonomy and decision-making ability risks being overlooked and made fit the service structure, rather than the other way around. Valuing and maintaining a person's autonomy also means including the person with YOD in all decision-making related to them. The example provided by Bakker and colleagues (2010) where a man with YOD, who had been placed in a home for older persons with dementia where he was greatly unhappy, and whose behavioural issues decreased and wellbeing improved when he was moved to a special care unit for person with YOD, is very telling: a holistic approach, taking into account the person with YOD, their needs and their wishes, as well as participation in decision-making, must be part of all service provision for persons with YOD.

Noirín's statement that *"if I had cancer, believe you me, I'd have support, I'd have support, but because I have dementia it doesn't, there isn't the support..."* is hard to disagree with, as decades of showcasing the lack of supports and the proven benefits of providing it have not achieved any major change in the situation. As the findings in this study unequivocally have shown, persons with YOD in Ireland are underserved and underprovided, and service provision and tailored supports specifically suited to their needs must be developed and rolled out across the country.

7.3.3 Challenging stigma to live well

The issue of stigma was a continuous presence in the findings of this research, both explicitly and implicitly. The hurtful experience of having an acquaintance obviously avoid you in the supermarket, or having people gossip about your illness, were experiences that the participants retold with stoicism. However, a lot of implicit stigma and self-censoring was also evident in the interviews. Sean and Aisling were reluctant to tell friends and extended family about Sean's diagnosis; only a very small circle of immediate family and select friends knew he had YOD. This, in combination with the limited services available, left Aisling to carry nearly all the responsibility for keeping Sean occupied in a meaningful way.

The muddled and confusing pathways to care, the poor disclosure procedures and the very limited provision of services that were all part of the findings in this study are all also touched by stigma. Noirín's comparison of dementia to cancer is a very thought-provoking one, in that the current low level of services and the lack of a pathway to care would be outrageous in relation to cancer. The stigma and nihilism surrounding dementia, and its continued portrayal as the worst of all illnesses (Cahill, 2018) all contribute to the sense that nothing can be done.

Without forcefully, actively and vigorously challenging such stigma, the detrimental impact on dementia in general, and YOD in particular and in relation to this study, will not end.

A number of the participants in this study were active campaigners for persons with YOD, and their activism had become a large part of their identity. As part of their advocacy work, they challenged stigma through being public about their illness and how it had affected their lives. Their perceptions and experiences were a huge strength of this thesis, as they were able to provide incomparable insight into their determination and impressive personal fight against stigma. It was, however, also a weakness as their unparalleled resolve and strength of character were truly extraordinary, meaning that they and their activism were unique and atypical. Nevertheless, their great ability in campaigning for persons with YOD against stigma and other issues was and is a much needed way of shining a light on the stigma around YOD, and importantly their campaigning also highlights the fact that many of the issues around stigma are systemic. There is only so much even a genuinely extraordinary person can achieve, and the efforts to dispel the stigma around dementia must not be left to those with the illness, but its systemic and societal roots must be acknowledged and tackled from the top down.

Some of the participants who were not involved in activism also challenged stigma, albeit in a more indirect way; by being open with their surroundings about their illness and their situation, participants such as Fionn, and Niamh, had found that their family and friends were happy to help in any way they could, be it spending time together on a regular basis, or helping in relation to more practical matters. Even where there was not a similarly positive engagement, such as for Tadgh, where some friends remained absent, there was nevertheless benefit to their openness, such as their tight-knit community keeping an eye on Tadgh when he was out on his own. The major findings in relation to stigma in this thesis confirm that that education, knowledge and above all awareness of what dementia actually is, is the most effective way of combatting dementia (Lockeridge & Simpson, 2013; Werner et al., 2019).

Fionn and Maeve's proactive and conscious approach to Fionn's YOD showed a strong sense of awareness of their situation, which Millenaar and colleagues (2017) found in their study to be an important variable for people with YOD to be able to keep participating in important aspects of daily living. Neither Fionn or Maeve were claiming that their situation was easy, or that they had not and were not going through difficult times and continuously facing new battles as Fionn's illness developed: however, they still kept up their meaningful activities and focused on abilities rather than deficits. Retelling the analogy used by their doctor of the heart disease patient, Maeve emphasised that this was helpful for them in their outlook, which she

summarised as *“anything we can do we will do”*. Living in the moment and doing their very best to use the support of family and friends, and their own initiative, they were able to live well with Fionn’s condition, alongside the many obstacles they also faced.

Noírín’s positive experience of cognitive rehabilitation echoes the study carried out by Bjoernstad Tonga and colleagues, which looked at whether a structured cognitive behavioural rehabilitation programme could be beneficial for persons with YOD with depressive symptoms. A combination of listing and carrying out enjoyable activities, and using a pocket calendar to help the person structure their time, but also to remind them what they had done and help them see that they had been busy, proved beneficial in their case study (Bjoernstad Tonga et al., 2016).

While Noírín’s life was obviously very different from before the illness, and she had gone through a period where she mourned what should have/would have been, the cognitive rehabilitation had given her some type of control over her life. She was quick to point out that the advocacy work she was doing was so others would not have to suffer the way she suffered after diagnosis, falling into a black hole, and going through a living hell, but at this stage in her experience she has moved far from that hole. Her description of struggling and suffering, so illustrative of the findings in this study that it made the title of this thesis, eloquently sums up the contradiction of living well with YOD: *“you know people think I’m suffering and I say to them I’m struggling I’m not suffering, yes I’m struggling with my illness but certainly I’m not suffering with it”*.

The effect of cognitive rehabilitation, a fairly simple intervention, was crucial to facilitating a better quality of life with YOD. However, as with all things relating to services, the overall difficulty of accessing services affect the ability to live well. Fintan was the participant whose life was probably the most similar to that pre-diagnosis. He was still working, which was a major difference from the other participants. He highlighted that he was lucky in that he was able to be open about his YOD in work and not get much of a reaction, as he worked in the creative arts where it was more common for people to be different, and people tended to be more open-minded. He had also set in place extra supports at work in the shape of a more involved assistant, who was able to keep a closer eye on things should anything fall through the cracks.

While Fintan’s continuation in the workplace was a testament to Roach’s argument that it is possible for a person with YOD to live well with dementia and work well with dementia (Roach, 2017), it was also made possible by his own circumstances. His solution to enable him

to continue to work was very proactive, thought-through and practical, but it depended on being able to introduce and pay an assistant in his workplace. As Fintan was self-employed, he had more leeway, and also had the financial possibility to go ahead. However, for a similar simple yet pragmatic solution to be accessible to other persons with YOD, buy-in from both employer and some type of funding may be necessary, to ensure the opportunities were fairly available to all.

Living well does in no way imply that the person was living blissfully with no problems as a result from their YOD; in many cases problems were still plentiful, the sadness over the diagnosis still present, and struggles still apparent. Nevertheless, there still existed a certain will to somehow live well with YOD, and each individual took their own steps towards this. Whether through adopting diet or fitness regimes that helped with wellbeing, or ensuring social contact and physical activity continued and increased, or working for better services and less stigma through awareness-raising and advocacy, the quest to live well with dementia was continuous. This quest revealed an optimism; not for a miracle cure or unrealistic expectations, but rather an optimism that said that despite having dementia, life can still be worth living, with enjoyment and pleasure and meaning, and there are steps that an individual can take to make this happen.

This finding flies in the face of stigma, and is the reason that I have chosen to combine the two in this final section of the thesis. It can be argued that living well with YOD is simply living without stigma, whereby the participant has challenged the stigma and is reaping the benefits of doing so. While it is not possible for an individual to disassociate from the stigma connected with YOD because so much of it is systemic, such as underfunding and disregard for services, or the lack of knowledge of healthcare professionals, trying simply to live well in whatever way possible for the individual is nevertheless going against the dictates of stigma. The stigma surrounding YOD must be challenged, on all fronts and in all manners; eradicating stigma will go a long way towards easing some of the issues experienced by persons with YOD, and enable them to live well with their illness.

7.4 Lessons learnt

While writing this thesis, things became apparent that I would have done differently if I were to plan this study from the beginning again. These were chiefly related to methodology, and while these learnings do not mean that the research is defective in any way, they are

nevertheless lessons of interest, both for a prospective researcher, and from my own point of view reflecting on my development throughout the research.

The main learning from this experience is related to the size of the sample. As discussed in section 3.4.1 (Sampling), in IPA participant sample sizes tend to be quite small, because of the great detail of the analysis. Despite this clearly being spelled out in the literature, described bluntly by Smith and colleagues as “the issue is quality, not quantity” (2009, p. 51), I still thought that for some reason I needed a large sample size, and that in order to get enough data and relevant findings the sample size would have to be bigger than only a few participants. At this early stage I had not fully grasped the extent to which IPA’s idiographic approach would provide a large amount of very rich data, and that combined with the researcher reflexivity meant that the analysis and results were extremely detailed.

The great level of detail in IPA meant that a substantial volume of data came from each interview. The richness of the data and the large amount of it meant that a lot had to be excluded from the thesis, as it would not be possible to include it all. This meant many difficult choices, re-writes, deletions, re-insertions, re-deletions, and much agonising over what to include, what to take out, and whether I was doing the participants’ stories justice. If I were to do this study again, I would have believed the literature, ignored my internalised ‘quantitative critic’ pushing for a larger sample size, and have limited the number of participants to maximum of five, maybe even less. To my relief, the literature does note (Smith et al., 2009) that sample sizes tend to be bigger among first-time or unexperienced IPA researchers, and with experience and the development of skills, the sample size becomes smaller; so this learning is a common feature in IPA, and in my case one that I had to learn the hard way.

Another learning relates to the participation of partners/spouses in the interview. As outlined in section 3.5.1 (In-depth interviews), of the ten participants, five had their partner or spouse present. One issue with having partners/spouses present is that the person with YOD may not speak freely, especially about their own fears and worries, out of concerns for their partner/spouse and not wanting to upset them. However, despite this I did not feel that it was appropriate to not allow a partner/spouse to be present. A more pressing issue when it comes to partners/spouses being present was the balance of who spoke more. While all efforts were made to keep the focus on the person with dementia, and to ensure that they were not sidelined in any way, this was not always possible. Especially in two of the interviews, Tadgh and Caoimhe and Seamus and Bláthnaid, the partner/spouse was the one who spoke significantly more.

While the experiences and observations shared by the partners/spouses in these two cases were significant and very pertinent, it was nevertheless not lost on me that this was not fully in line with my intention of keeping the person with YOD and their experiences in the centre at all times, and for the person's voice to be heard. It is difficult to know if I should have insisted on meeting with the person alone, as this may have alienated prospective participants who did want their partners/spouses present, or who did not feel comfortable meeting with me alone; or if I perhaps should have explored better ways to ensure that the partners/spouses' participation was kept at a minimum. The learning I took from this is that there are many complexities and that no one answer is necessarily correct, but that I should have given this more thought and consideration in the planning stages of the study.

7.5 Limitations of the study

In addition to the learnings mentioned in the above section, there were a number of other limitations to this study. The first one is that of the potential for gatekeeper bias, in relation to sourcing participants. I outlined my reasons for opting for gatekeepers to recruit participants rather than direct recruitment in section 3.4.3 (Gatekeepers), but the issue of gatekeeper bias is nevertheless important to acknowledge. I reasoned that gatekeepers, many of whom were clinicians, or otherwise very experienced in dealing with persons with dementia, would approach persons they believed would have the cognitive ability to participate and thereby provide an extra assurance that unsuitable recruitment would be avoided as much as possible. However, this choice meant that what I gained in reassurance that recruitment would be appropriate, I lost in potential participants whom for some reason, apart from cognitive abilities, were not approached by the gatekeeper. While this was a decision made by me in full awareness of the implications, it is nevertheless a shortcoming of the study and necessary to recognise.

Another shortcoming of the study which seems obvious at the time of writing this section, in 2021, but was not so obvious in 2012/2013, was the inclusion of persons with YOD in the planning and creation of the study. One of my main concerns while formulating the study was to keep the person with dementia central, and to make sure that their voice was given free rein was for me the most important aspect of the study. Despite this, at no point did I stop and think that it might be useful to consult a person with YOD when planning the study, and get their experience or opinion on areas of focus, or issues such as what a person with YOD may like to see included in the study, what areas or topics were of specific concern, and in what ways could participation be facilitated. Including and consulting the research subject in the

creation of the research is more commonplace today, however it unfortunately did not even cross my mind back in 2012/2013 when I was creating the study, something I greatly regret looking back. Having the insight and experience of a person with YOD when I planned the study would have made it more inclusive and would have been a real way of having the person with YOD be central to the study, not only in participation but also in the planning and development stages.

7.6 Concluding thoughts

This topic was chosen as I was interested in finding out more about people with young onset dementia in Ireland, and their experiences of the disease in relation to a number of different issues. The findings as detailed in this PhD thesis, and as summarised in this chapter, were underpinned by a paradoxical combination: while the suffocating presence of stigma was part of virtually all issues, so was the wish to somehow work to live better and to live well with the diagnosis, for as long as was possible.

While a diagnosis of YOD was described as a living hell, and something that robbed the participants of their future, there still existed a wish to continue with life to the best of their ability. Cheston and Bender describe the threat to the sense of self that the disappearance of positive social interactions has as “...through our interactions with others, our friendships, our love affairs etc that we become who we are” (Cheston & Bender, 1999, p. 232). These positive social interactions, and the benefits that they bring, were at the core of the experiences of the participants, who were trying and hoping to inasmuch as possible to maintain a sense of self and a meaningful life for as long as possible.

Tolhurst and colleagues (2014) point out that focusing only on the negatives and losses of dementia, and overlooking the positives and the life that still remains, does not differ much from the biomedical perspective, which focuses only on degenerative aspects. Rather, an approach where the person with YOD’s human rights and abilities are respected and celebrated, and where the stigma which underpins so many of the issues around YOD are challenged, both personal and systemic stigma, can create a situation where YOD and those that have it are not viewed with fear and pity. As Shakespeare and colleagues put it, it is not possible to create a world where it would be easy to have dementia, but there should be a world where it is possible to live better with it (Shakespeare et al., 2019). This thesis has outlined the many difficulties that persons with YOD experience in Ireland, however the

participants' also showed that with the right supports in place, life with YOD, while obviously different from their previous lives, can still be a life lived with dignity, quality, autonomy, pleasure and enjoyment.

BIBLIOGRAPHY

- Aslett, H. J., Huws, J. C., Woods, R. T., & Kelly-Rhind, J. (2019). 'This is Killing me Inside': The Impact of Having a Parent with Young-Onset Dementia. *Dementia*, 18(3), 1089–1107. <https://doi.org/10.1177/1471301217702977>
- Baker, J. D. (2016). The Purpose, Process, and Methods of Writing a Literature Review. *AORN Journal*, 103(3), 265–269. <https://doi.org/10.1016/j.aorn.2016.01.016>
- Bakker, C., De Vugt, M. E., Vernooij-Dassen, M., Van Vliet, D., Verhey, F. R. J., & Koopmans, R. T. C. M. (2010). Needs in early onset dementia: A qualitative case from the NeedYD study. *American Journal of Alzheimer's Disease and Other Dementias*, 25(8), 634–640. <https://doi.org/10.1177/1533317510385811>
- Baldwin, C. (2008). Narrative(,) citizenship and dementia: The personal and the political. *Journal of Aging Studies*, 22(3), 222–228. <https://doi.org/10.1016/j.jaging.2007.04.002>
- Bartlett, H., & Martin, W. (2002). Ethical issues in dementia care research. In Heather Wilkinson (Ed.), *The Perspectives of People with Dementia Research Methods and Motivations* (p. 256). Jessica Kingsley Publishers.
- Bartlett, R., & O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies*, 21(2), 107–118.
- Berger, R. (2015). Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qualitative Research*, 15(2), 219–234. <https://doi.org/10.1177/1468794112468475>
- Birt, L., Poland, F., Csipke, E., & Charlesworth, G. (2017). Shifting dementia discourses from deficit to active citizenship. *Sociology of Health & Illness*, 39(2), 199–211.
- Bjoernstad Tonga, J., Arnevik, E. A., Werheid, K., & Ulstein, I. D. (2016). Manual-based cognitive behavioral and cognitive rehabilitation therapy for young-onset dementia: A case report. *International Psychogeriatrics*, 28(3), 519–522. <https://doi.org/10.1017/S1041610215001696>
- Blaikie, N. (2007). *Approaches to Social Enquiry Second Edition* (2nd ed.). Polity Press.
- Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology & Health*, 21(1), 87–

108.

- Byrne, J. A. (2016). Improving the peer review of narrative literature reviews. *Research Integrity and Peer Review*, 1(12), 1–4. <https://doi.org/10.1186/s41073-016-0019-2>
- Cahill, S., Clark, M., O'Connell, H., Lawlor, B., Coen, R., Walsh, C. (2008). The attitudes and practices of general practitioners regarding dementia diagnosis in Ireland. *International Journal of Geriatric Psychiatry*, 23(7), 663–669. <https://doi.org/10.1002/gps.1956>
- Cahill, S., Clark, M., Walsh, C., O'Connell, H., & Lawlor, B. (2006). Dementia in primary care: The first survey of Irish general practitioners. *International Journal of Geriatric Psychiatry*, 21(4), 319–324. <https://doi.org/10.1002/gps.1464>
- Cahill, Suzanne. (2018). *Dementia and human rights*. Policy Press.
- Cahill, Suzanne, O'Shea, E., & Pierce, M. (2012). *Creating Excellence in Dementia Care A Research Review for Ireland's National Dementia Strategy*.
- Cahill, Suzanne, Pierce, M., & Moore, V. (2014). A national survey of memory clinics in the Republic of Ireland. *International Psychogeriatrics*, 26(4), 605–613.
- Carone, L., Tischler, V., & Dening, T. (2016). Football and dementia: A qualitative investigation of a community based sports group for men with early onset dementia. *Dementia*, 15(6), 1358–1376. <https://doi.org/10.1177/1471301214560239>
- Carter, L., O'Neill, S., Keogh, F., Pierce, M., & O'Shea, E. (2019). Intensive home care supports, informal care and private provision for people with dementia in Ireland. *Dementia, Online ahe*, 1–15. <https://doi.org/10.1177/1471301219863580>
- Chaplin, R., & Davidson, I. (2016). What are the experiences of people with dementia in employment? *Dementia*, 15(2), 147–161. <https://doi.org/10.1177/1471301213519252>
- Chaston, D. (2011). Between a rock and a hard place: Exploring the service needs of younger people with dementia. *Contemporary Nurse*, 39(2). <https://doi.org/10.5172/conu.2011.39.2.130>
- Chemali, Z., Schamber, S., Tarbi, E.C., Acar, D., Avila-Urizar, M. (2012). Diagnosing early onset dementia and then what ? A frustrating system of aftercare resources. *International Journal of General Medicine*, 5, 81–86. <https://doi.org/10.2147/IJGM.S26523>
- Cheston, R., & Bender, M. (1999). *Understanding Dementia The Man with the Worried Eyes*. Jessica Kingsley Publishers.

- Clarke, C. L., & Keady, J. (2002). Getting down to brass tacks A discussion of data collection with people with dementia. In Heather Wilkinson (Ed.), *The Perspectives of People with Dementia Research Methods and Motivations*. Jessica Kingsley Publishers.
- Clemerson, G., Walsh, S., & Isaac, C. (2014). Towards living well with young onset dementia: An exploration of coping from the perspective of those diagnosed. *Dementia*, 13(4), 451–466.
- Connolly, S., Gillespie, P., O'Shea, E., Cahill, S., & Pierce, M. (2014). Estimating the economic and social costs of dementia in Ireland. *Dementia*, 13(1), 5–22.
<https://doi.org/10.1177/1471301212442453>
- Creswell, J. (2007). *Qualitative Inquiry and Research Design Choosing Among Five Approaches Second Edition*. Sage Publications.
- Crotty, M. (1998). *The Foundations of Social Research Meaning and Perspective in the Research Process*. Sage Publications.
- Denscombe, M. (2007). *The Good Research Guide for small-scale research projects*. Open University Press.
- Department of Health. (2014). *The Irish National Dementia Strategy*.
- Department of Health and National Dementia Office. (2018). *Mid-Term Review of the Implementation of the National Dementia Strategy*.
- Dewing, J. (2002). From ritual to relationship: a person-centred approach to consent in qualitative research with older people who have dementia. *Dementia*, 1(2), 1935–1943.
- Dixon, J., Laing, J., & Valentine, C. (2020). A human rights approach to advocacy for people with dementia: A review of current provision in England and Wales. *Dementia*, 19(2), 221–236. <https://doi.org/10.1177/1471301218770478>
- Dodgson, J. E. (2019). Reflexivity in Qualitative Research. *Journal of Human Lactation*, 35(2), 220–222. <https://doi.org/10.1177/0890334419830990>
- Downs, M. (1997). The Emergence of the Person in Dementia Research. *Ageing and Society*, 17(5), 597–607.
- Draper, B., & Withall, A. (2016). Young onset dementia. *Internal Medicine Journal*, 46(7), 779–786. <https://doi.org/10.1111/imj.13099>

- Fisk, J. D., Beattie, L. B., Donnelly, M., Byszewski, A., & Molnar, F. J. (2007). Disclosure of the diagnosis of dementia. *Alzheimer's and Dementia*, 3(4), 404–410.
- Fox, S., Cahill, S., McGown, R., & Kilty, C. (2020). *Young Onset Dementia: A Review of Diagnostic and Post-diagnostic Processes and Pathways*.
- Green, H. (2014). Use of theoretical and conceptual frameworks in qualitative research. *Nurse Researcher*, 21(6), 34–38.
- Haase, T. (2005). *Early-Onset Dementia The Needs of Younger People with Dementia in Ireland*.
- Harris, P. B., & Keady, J. (2009). Selfhood in younger onset dementia: Transitions and testimonies. *Aging & Mental Health*, 13(3), 437–444.
- Harvey, R., Roques, P., Fox, N., & Rossor, M. (1998). CANDID - Counselling and diagnosis in dementia: a national telemedicine service supporting the care of younger patients with dementia. *International Journal of Geriatric Psychiatry*, 13(6), 381–388.
- Hellström, I., Nolan, M., Nordenfelt, L., & Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, 14(5), 608–619.
<https://doi.org/10.1177/0969733007080206>
- Hennelly, N., & O'Shea, E. (2017). Personhood, dementia policy and the Irish National Dementia Strategy. *Dementia*, 18(5), 1810–1825.
<https://doi.org/10.1177/1471301217729232>
- Hewitt, P., Watts, C., Hussey, J., Power, K., & Williams, T. (2013). Does a Structured Gardening Programme Improve Well-being in Young-Onset Dementia? A Preliminary Study. *British Journal of Occupational Therapy*, 76(8), 355–361.
<https://doi.org/10.4276/030802213X13757040168270>
- Hoppe, S. (2019). Shifting uncertainties in the pre-diagnostic trajectory of early-onset dementia. *Dementia*, 18(2), 613–629. <https://doi.org/10.1177/1471301216687436>
- Hughes, J. C. (2019). Citizenship and authenticity in dementia: A scoping review. *Maturitas*, 125, 11–16. <https://doi.org/10.1016/j.maturitas.2019.04.001>
- Illiffe, S., Robinson, L., Brayne, C., Goodman, C., Rait, G., Manthorpe, J., Ashley, P., & Group, D. P. C. C. S. (2009). Primary care and dementia: 1. Diagnosis, screening and disclosure. *International Journal of Geriatric Psychiatry*, 24(9), 895–901.
<https://doi.org/10.1002.gps.2204>

- Johannessen, A., Engedal, K., & Thorsen, K. (2015). Adult children of parents with young-onset dementia narrate the experiences of their youth through metaphors. *Journal of Multidisciplinary Healthcare*, 8, 245–254. <https://doi.org/10.2147/JMDH.S84069>
- Johannessen, A., Engedal, K., & Thorsen, K. (2016a). Coping efforts and resilience among adult children who grew up with a parent with young-onset dementia: A qualitative follow-up study. *International Journal of Qualitative Studies on Health and Well-Being*, 11, 1–12. <https://doi.org/10.3402/qhw.v11.30535>
- Johannessen, A., Engedal, K., & Thorsen, K. (2016b). Family Carers of People with Young-Onset Dementia: Their Experiences with the Supporter Service. *Geriatrics*, 1(4), 28. <https://doi.org/10.3390/geriatrics1040028>
- Kaiser, S., & Panegyres, P. K. (2006). The psychosocial impact of young onset dementia on spouses. *American Journal of Alzheimer's Disease and Other Dementias*, 21(6), 398–402. <https://doi.org/10.1177/1533317506293259>
- Kitwood, T. (1997a). *Dementia Reconsidered The peson comes first*. Open University Press.
- Kitwood, T. (1997b). The experience of dementia. *Aging & Mental Health*, 1(1), 13–22. <https://doi.org/10.1080.13607869757344>
- Knapp, M., Comas Herrera, A., Somani, A., & Banerjee, S. (2007). *Dementia: International comparisons Summary report for the National Audit Office*.
- Koopmans, R., & Rosness, T. (2014). Young onset dementia - what does the name imply? *International Psychogeriatrics*, 26(12), 1931–1933. <https://doi.org/10.1017/S1041610214001574>
- Kumar, R. (2005). *Research Methodology A Step-by-Step Guide for Beginners Second Edition*. Sage Publications.
- Kuruppu, D. K., & Matthews, B. R. (2013). Young-Onset Dementia. *Seminars in Neurology*, 33(4), 365–385. <https://doi.org/10.1055/s-0033-1359320>.Young-Onset
- Lambert, M. A., Bickel, H., Prince, M., Fratiglioni, L., Von Strauss, E., Frydecka, D., Kiejna, A., Georges, J., & Reynish, E. L. (2014). Estimating the burden of early onset dementia; systematic review of disease prevalence. *European Journal of Neurology*, 21(4), 563–569. <https://doi.org/10.1111/ene.12325>
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative

- phenomenological analysis. *Qualitative Research in Psychology*, 3(2), 102–120.
- Larochette, C., Wawrziczny, E., Papo, D., Antoine, P., & Pasquier, F. (2019). An acceptance, role transition, and couple dynamics-based program for caregivers: A qualitative study of the experience of spouses of persons with young-onset dementia. *Dementia*.
<https://doi.org/10.1177/1471301219854643>
- Lockeridge, S., & Simpson, J. (2013). The experience of caring for a partner with young onset dementia: How younger carers cope. *Dementia*, 12(5), 635–651.
<https://doi.org/10.1177/1471301212440873>
- Mayrhofer, A. M., Mathie, E., McKeown, J., Goodman, C., Irvine, L., Hall, N., & Walker, M. (2018). Young onset dementia: Public involvement in co-designing community-based support. *Dementia*. <https://doi.org/10.1177/1471301218793463>
- McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing*, 19(13–14), 1935–1943.
<https://doi.org/10.1111/j.13b5-2702.2009.03136.x>
- Medicinsk, S. U. S. beredning för. (2008). *Dementia - Etiology and Epidemiology*.
- Millenaar, J. K., Hvidsten, L., De Vugt, M. E., Engedal, K., Selbaek, G., Bruun Wyller, T., Johannessen, A., Haugen, P. K., Bakker, C., Van Vliet, D., Koopmans, R. T. C. M., Verhey, F. R. J., & Kersten, H. (2017). Determinants of quality of life in young onset dementia - results from a European multicenter assessment. *Aging & Mental Health*, 21(1), 24–30.
<https://doi.org/10.1080/13607863.2016.1232369>
- Millenaar, J. K., Van Vliet, D., Bakker, C., Vernooij-Dassen, M. J. F. J., Koopmans, R. T. C. M., Verhey, F. R. J., & De Vugt, M. E. (2014). The experiences and needs of children living with a parent with young onset dementia: Results from the NeedYD study. *International Psychogeriatrics*, 26(12), 2001–2010. <https://doi.org/10.1017/S1041610213001890>
- Moore, V., & Cahill, S. (2013). Diagnosis and disclosure of dementia - A comparative qualitative study of Irish and Swedish General Practitioners. *Aging and Mental Health*, 17(1), 77–84.
<https://doi.org/10.1080/13607863.2012.692763>
- Novek, S., Shooshtari, S., & Menec, V. H. (2016). Comparing the Overall Health, Stress, and Characteristics of Canadians with Early-Onset and Late-Onset Dementia. *Journal of Aging and Health*, 28(6), 1016–1037. <https://doi.org/10.1177/0898264315615575>
- O'Connor, D., Phinney, A., Smith, A., Small, J., Purves, B., Perry, J., Drance, E., Donnelly, M.,

- Chaudhury, H., & Beattie, L. (2007). Personhood in dementia care. *Dementia*, 6(1), 121–142.
- O'Shea, E. (2007). *Implementing Policy for Dementia Care in Ireland The Time for Action is Now*.
- O'Shea, E., Cahill, S., & Pierce, M. (2017). Conclusion: Towards a Second Dementia Strategy. In E. O'Shea, S. Cahill, & M. Pierce (Eds.), *Developing and Implementing Dementia Policy in Ireland*. Centre for Economic and Social Research on Dementia, National University of Ireland Galway.
- O'Shea, E., Cahill, S., Pierce, M., Hennelly, N., & Carney, P. (2017). Introduction. In E. O'Shea, S. Cahill, & M. Pierce (Eds.), *Developing and Implementing Dementia Policy in Ireland*. Centre for Economic and Social Research on Dementia, National University of Ireland Galway.
- O'Shea, E., & Carney, P. (2016). *Dementia Paying Dividends A report on The Atlantic Philanthropies Investment in Dementia in Ireland*.
- O'Shea, E., & Monaghan, C. (2017). An economic analysis of a community-based model for dementia care in Ireland: a balance of care approach. *International Psychogeriatrics*, 29(7), 1175–1184. <https://doi.org/10.1017/S1041610217000400>
- O'Shea, E., & O'Reilly, S. (1999). *An Action Plan for Dementia*.
- Ólafsdóttir, M., Skoog, I., & Marcusson, J. (2000). Detection of Dementia in Primary Care: The Linköping Study'. *Dementia and Geriatric Cognitive Disorders*, 11(4), 223–229.
- Pang, R. C. K., & Lee, D. T. F. (2019). Finding positives in caregiving: The unique experiences of Chinese spousal caregivers of persons with young-onset dementia. *Dementia*, 18(5), 1615–1628. <https://doi.org/10.1177/1471301217724026>
- Pesonen, H. M., Remes, A. M., & Isola, A. (2011). Ethical aspects of researching subjective experiences in early-stage dementia. *Nursing Ethics*, 18(5), 651–661. <https://doi.org/10.1177/0969733011408046>
- Pierse, T., O'Shea, E., & Carney, P. (2019). Estimates of the prevalence, incidence and severity of dementia in Ireland. *Irish Journal of Psychological Medicine*, 36(2), 129–137. <https://doi.org/10.1017/ipm.2018.31>
- Pierse, Tom, & O'Shea, E. (2017). The Economics and Financing of Dementia in Ireland. In E.

- O'Shea, S. Cahill, & M. Pierce (Eds.), *Developing and Implementing Dementia Policy in Ireland*. Centre for Economic and Social Research on Dementia, National University of Ireland Galway.
- Ritchie, J. (2003). The applications of qualitative methods to social research. In *Qualitative Research Practice A Guide for Social Science Students and Researchers* (pp. 24–46). Sage Publications.
- Ritchie, L., Banks, P., Danson, M., Tolson, D., & Borrowman, F. (2015). Dementia in the workplace: A review. *Journal of Public Mental Health, 14*(1), 24–34.
<https://doi.org/10.1108/JPMH-04-2014-0015>
- Roach, P. (2017). Young onset dementia: Negotiating future workplace roles and identities. *Dementia, 16*(1), 5–8. <https://doi.org/10.1177/1471301216674420>
- Roach, P., Keady, J., Bee, P., & Hope, K. (2008). Subjective experiences of younger people with dementia and their families: implications for UK research, policy and practice. *Reviews in Clinical Gerontology, 18*(02), 165–174.
- Rossor, M. N., Fox, N. C., Mummery, C. J., Schott, J. M., & Warren, J. D. (2010). The diagnosis of young onset dementia. *The Lancet: Neurology, 9*(8), 793–806.
[https://doi.org/10.1016/S1474-4422\(10\)70159-9](https://doi.org/10.1016/S1474-4422(10)70159-9)
- Shakespeare, T., Zeilig, H., & Mittler, P. (2019). Rights in Mind: Thinking Differently About Dementia and Disability. *Dementia, 18*(3), 1075–1088.
<https://doi.org/10.1177/1471301217701506>
- Sherrat, C., Soteriou, T., & Evans, S. (2007). Ethical issues in social research involving people with dementia. *Dementia, 6*(4), 463–479.
- Slaughter, S., Cole, D., Jennings, E., & Reimer, M. . (2007). Consent and assent to participate in research from people with dementia. *Nursing Ethics, 14*(1), 27–40.
- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology, 1*(1), 39–54.
- Smith, J. A., & Eatough, V. (2007). *Interpretative phenomenological analysis* (E. Lyons & A. Coyle (eds.); Analysing). Sage Publications.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis Theory*

Method and Research. Sage Publications.

Smith, J. A., & Osborn, M. (2008). *Interpretative Phenomenological Analysis* (J. A. Smith (ed.); Qualitativ). Sage Publications.

Storey, L. (2007). *Doing Interpretative Phenomenological Analysis* (E. Lyons & A. Coyle (eds.); Analysing). Sage Publications.

Svanberg, E., Spector, A., & Scott, J. (2011). The impact of young onset dementia on the family: a literature review. *International Psychogeriatrics*, 23(3), 356–371.

Swedish Council on Technology Assessment in Healthcare (SBU - Statens beredning för medicinsk utvärdering). (2008). *Dementia - Etiology and Epidemiology A Systematic Review*.

Teles Vieira, R., Caixeta, L., Machado, S., Cardoso Silva, A., Egidio Nardi, A., Arias-Carrion, O., & Giovanni Carta, M. (2013). Epidemiology of early-onset dementia: a review of the literature. *Clinical Practice & Epidemiology in Mental Health*, 9, 99–95.

Thorsen, K., Nascimento Dourado, M. C., & Johannessen, A. (2020). Developing dementia: The existential experience of the quality of life with young-onset dementia - A longitudinal case study. *Dementia*, 19(3), 878–893.

Tolhurst, E., Bhattacharyya, S., & Kingston, P. (2014). Young onset dementia: The impact of emergent age-based factors upon personhood. *Dementia*, 13(2), 193–206.

Van Vliet, D., De Vugt, M. E., Bakker, C., Pijnenburg, Y. A. L., Vernooij-Dassen, M. J. F. J., Koopmans, R. T. C. M., & Verhey, F. R. J. (2013). Time to diagnosis in young-onset dementia as compared with late-onset dementia. *Psychological Medicine*, 43(2), 423–432. <https://doi.org/10.1017/S0033291712001122>

Van Vliet, Deliane, De Vugt, M. E., Bakker, C., Koopmans, R. T. C. M., Pijnenburg, Y. A. L., Vernooij-Dassen, M. J. F. J., & Verhey, F. R. J. (2011). Caregivers' perspectives on the pre-diagnostic period in early onset dementia: A long and winding road. *International Psychogeriatrics*, 23(9), 1393–1404. <https://doi.org/10.1017/S1041610211001013>

Van Vliet, Deliane, Persoon, A., Bakker, C., Koopmans, R. T. C. M., De Vugt, M. E., Bielderma, A., & Gerritsen, D. L. (2017). Feeling useful and engaged in daily life: Exploring the experiences of people with young-onset dementia. *International Psychogeriatrics*, 29(11), 1889–1898. <https://doi.org/10.1017/S1041610217001314>

- Werner, P., Shpigelman, C. N., & Raviv Turgeman, L. (2019). Family caregivers' and professionals' stigmatic experiences with persons with early-onset dementia: a qualitative study. *Scandinavian Journal of Caring Sciences*, 20.
<https://doi.org/10.1111/scs.12704>
- Wilkinson, H. (2002). Including people with dementia in research Methods and motivations. In *The Perspectives of People with Dementia Research Methods and Motivations*. Jessica Kingsley Publishers.
- World Health Organisation. (2012). *Dementia A Public Health Priority*.
- World Health Organisation. (2015). *Thematic briefing: Ensuring a human rights-based approach for people living with dementia*.
https://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_human_rights.pdf
- World Health Organisation. (2017). *Global action plan on the public health response to dementia 2017 - 2025*.



Appendix A – Participant information sheet

Participant Information Sheet

Experiences of Young Onset Dementia and Accessing Health Care and Social Care Services in Ireland

Who is conducting the study?

My name is Vanessa Moore, and I am studying for a PhD in the School of Social Work and Social Policy at Trinity College Dublin.

I am funded by a Postgraduate Scholarship from the School of Social Work and Social Policy, Trinity College Dublin.

If you have any queries about this research, you can contact me (please see details at the end of this letter) or my supervisor Professor Virpi Timonen on 01-896 2950.

Aims of the study

The title of my study is: “Experiences of Young Onset Dementia and Accessing Health Care and Social Care Services in Ireland”.

The aim of the study is to get an insight into the experiences of people with young onset dementia, and how they access health care and social care services.

I am undertaking this study because there is not enough knowledge of the experiences, wishes and needs of those with young onset dementia.

I hope to interview people with young onset dementia. By doing this, I hope to achieve a more in-depth understanding of the lives and needs of people with young onset dementia.

Who is being asked to participate in this study?

- People who are under 65 years of age, and
- Who have a diagnosis of dementia (for a minimum of 12 months at the time of the interview), and
- freely consent to participating in the study.

If you fit the above description, please consider taking part in my study. Participation is voluntary.

Interview

If you decide to take part in this study, you will be asked to take part in an interview. The interview will take place at any location that is convenient for you, for example in your own home.

The interview will take between one to two hours. The interview will be recorded to ensure that your answers are accurately captured. I will ask you about the diagnosis, about your experiences with the health care system and with social care services, and about the impact of the dementia on your life.

You can stop the interview if you want to continue at a later time, or divide the interview up over two sessions. If you want to withdraw from the study at any stage, you can do so.

All information gathered will be kept confidential, and no names or identifying data will be disclosed. The recorded interviews will be written out and kept on computer files. After the work has been completed, the recordings will be destroyed and only the written-out interviews (transcripts) will be kept.

You will be able to get a copy of the transcript if you wish, either electronically or via mail. You can also get a copy of the final research report when it is finished, either send to you through email or the post.

The transcripts will be archived anonymously (that is, without any names) at the end of the study. This is only for the purposes of enabling further study by researchers who want to gain a better understanding of the lives, experiences, needs and wishes of people with young onset dementia.

Contact details

Thank you very much for considering taking part in my research.

If you would like to contact me for more information, or want to meet with me to find out more about the study, I would be happy to do so.

Please feel free to contact me through email or by phone:

Email: moorev@tcd.ie Phone: 086-8656307

With many thanks,

Vanessa Moore



Appendix B – Consent form

Experiences of Young Onset Dementia and Accessing Health Care and Social Care Services in Ireland

Consent Form

I am willing to be interviewed by Vanessa Moore from the School of Social Work and Social Policy in Trinity College Dublin.

This is for her PhD thesis entitled “Experiences of Young Onset Dementia and Accessing Health Care and Social Care Services in Ireland”.

- The purpose of the research has been explained to me. I have been given an opportunity to ask any questions I have about the research.
- I understand that my participation will contribute to research on experiences of young onset dementia. I understand that it will be used for a PhD thesis.
- I understand that my participation is entirely voluntary and that I can end my participation at any time.
- I understand that I can stop the interview at any time and continue it at another time if I so wish.
- I understand that I can get a copy of the interview transcript if I would like
- I agree that any information gathered in the interview may be used by the researcher for the purpose of writing the thesis and related publications and presentations.
- I understand that my anonymity will be maintained.
- I understand that the anonymised transcripts will be archived at the end of the study.

By signing below I confirm that I am willing to participate in this study and that I am willing to be contacted about participation in future studies related to this piece of research.

Signed: _____

Date: _____

Appendix C – Interview schedule

Interview Schedule

Introduction to interview: state that the Dictaphone has been turned on. Briefly outline again what the aims of the study is, and confirm that the person is happy to participate. Also confirm that the person has a diagnosis of dementia.

Awareness and Diagnosis of Dementia

Tell me about the time before you got the diagnosis.

-When did you first notice symptoms of memory decline?

-Can you give me examples?

-Did you notice the symptoms, or did those around you notice?

In what way did you approach the health services?

If it was a family member who approached them, how did they go about it?

Did you expect a diagnosis of dementia?

How did you react to the diagnosis?

What was your overall experience of the diagnostic process?

Interaction with Health Care and Social Care Services

What has been your experience of health care and social support services after diagnosis?

-Tell me about the first time you came into contact with services after your diagnosis?

-What service(s) was/were these?

-What did you think of them?

-Was there anything that struck you as positive, or not so good?

Do you have much interaction currently with the health care services?

Do you have much interaction currently with the social care services?

Do you think your service use will change in the future?

Overall experience of navigating the system and accessing care?

Impact of Dementia

How does dementia affect you personally?

How has dementia affected your working life?

How does the illness affect your family life: relationship with spouse/partner/children/parents?

Closing Questions

Is there something I haven't asked you that you think is relevant to our topic?

Is there anything you would like to ask me?

Is there anything else you would like to say?