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The suffering of the many Irish people who bought houses at the height of the economic boom with variable mortgages is a topical and telling demonstration of the difficulties of planning for the future. What seemed like a good idea in 2006 has become a millstone around many necks, putting huge strains on marriages and family life, and is deservedly a topic of national debate. Signing into a binding written commitment for their financial future has been a bitter experience for this large group of people: how much more painful might it be if they had signed into unhappy binding agreements about their future healthcare? The illusion that the future healthcare can be tightly defined is typified by the case for advance directives, an idea for which enthusiasm has unhappily out-stripped an increasingly critical biomedical literature¹. This ranges from their description by the majority of ICU staff in one US study as 'useless'² to clear problems which arise when advance directives are patently in conflict with the patient's best interests³.

A number of criticisms can be levelled at most forms of proposed advance care directives currently available in Ireland – the most prominent of which is Think Ahead www.thinkahead.ie, in part funded by Atlantic Philanthropies - as well as the recommendations of the Irish Law Reform Commission⁴. They are generally negative in nature, focussing on non-treatment rather than treatment, and offer an impoverished palette of responses to the demands of late-life complexity. A further major concern is the extent to which they may consciously or unconsciously reflect widespread ageism and prejudice against disability, a trend magnified by underprovision of gerontological nursing skills in many settings⁵. This was illustrated in an RTE documentary in 2009 which prefaced a discussion on end-of-life care with a video of a man with Parkinson's apparently aspirating on regurgitated feed from a gastrostomy tube. To any trained clinicians watching, the problem was a care issue in that he was being fed while recumbent – which hugely increases the risk of aspiration - and not necessarily that of the ethics of life support and disability, a point completely missed by the panel on the programme.

Combatting negativity about life with dementia and disability remains challenging, despite ground-breaking conceptual⁶, ethical⁷ and empirical study on preserved personhood and quality of life in dementia⁸. Research on personal growth in disability⁹, as well as the remarkable testimony of the Irish film-maker Simon Fitzmaurice on his struggle to ensure that he would be ventilated with his motor neuron disease¹⁰, should instil caution on those who might consider eschewing life-support in advance planning for a possible future disabling illness. This is especially relevant given the emotive video on the Think Ahead website whereby a relatively young fireman expresses a wish not to be on life support if there is 'no way back'.

Older people themselves understand that late life is also a time marked by complexity, increased inter-individual variability and unpredictability, and defer advance care planning to a time when the reality of illness and disability are salient, as displayed by a study from the first Irish longitudinal study on ageing¹¹. In the USA, it is a striking that many avoid engaging with advance directives in settings where the law mandates that they should be offered the opportunity to make one¹². For those that do make an advance directive, frequent changes are common¹³, and it is clear that patients do not desire a stark dichotomy between life-sustaining treatment and hospice care¹⁴. In addition, the heterogeneity of possible outcomes means that the methodology of assisted decision-making is less helpful¹⁵, unlike more specific decisions such as the use of respite care¹⁶.

So given that some form of advance care planning is clearly desirable at certain stages of health care,

what form of mechanisms might we put in place, building on the encouraging finding that Irish doctors consult appropriately with patients and their families when altering treatment intensity at the end of life¹⁷? Such care should be planned at a point where the patient has some experience and knowledge of the likely conditions. The plan should be developed with a healthcare professional who has in-depth knowledge of the relevant conditions. It should be possible to request positive, proactive care as well as treatment refusal. For example, given that the most likely scenario for impaired decision-making capacity in clinical practice arises from the two key illnesses of later life, dementia and stroke, specifying that those looking after the patient would have specific training in gerontology and dementia care would be reasonable¹⁸.

In this way, so that the patient's wishes can be interpreted in a sensitive fashion for as long as possible and flexible advance care preferences constructed that can adapt to changing circumstances and new therapeutic and palliative advances. Rather than binding my healthcare providers into an outdated view of a fast-changing medical landscape, the plan should be phrased in terms of advanced care preferences with a strong moral force rather than a legally binding directive¹⁹. This approach is supported by studies which show that in general patients trust their doctors to do the right thing²⁰.

The impending Irish legislation on mental capacity promotes the concept of co-decision-maker. This is a more useful concept than that of health-care proxy, a subtle but important emphasis on assisted decision-making, extending autonomy. Even in late dementia, a patient may make preferences clear by pulling out a tube or line, or by insisting in drinking despite a swallow disorder which means that liquids may spill into the lungs: what is most important is that the care staff know how to interpret and support these decisions. Bertrand Russell wrote that the demand for certainty is one which is natural to man, but is nevertheless an intellectual vice. There is an urgent need for Irish clinicians to inject clinical reality and relevant research into the national debate on advance care planning so as to develop new models which avoid early foreclosure on options for a full palette of care at the end of life.

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