

A Perspective on Advance Planning for end-of-life

An exploration of contemporary developments concerning
the concept and practice of Advance Planning, Advance Care
Planning and Advance Healthcare Directives



The Irish Hospice Foundation's Perspectives series aims to spark debate on vital topics in the fields of hospice care, death and dying by commissioning papers from key thinkers and offering our own view of what they propose. Previous Perspectives include:

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The Irish
**Hospice
Foundation**

Striving for the best care
at end of life for all

This paper explores contemporary developments concerning the concept and practice of advance planning.

A range of pertinent issues are discussed, including the terminology and scope of advance planning; the ethical, legal and policy context of advanced healthcare directives in Ireland; the rationale for engaging in advance healthcare directives; and barriers to, and drivers of, advance planning.

The Irish Hospice Foundation actively supports the notion of advance planning for end-of-life as an important personal decision and a key aspect of public policy. It is hoped that this paper will help to inform the ongoing debate in Irish society, and to shape the IHF's response to advance planning for end-of-life.

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Irish Hospice Foundation

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FOREWORD

The Irish Hospice Foundation (IHF) is a national charity dedicated to all matters relating to dying, death and bereavement in Ireland. Our mission is to strive for the best care at end-of-life for all so that everyone is enabled, insofar as possible, to have a 'good death'.

We believe that advance care planning (ACP) and more specifically, advance healthcare directives (ACD), comprise an important component of the quality of care that can assist people approaching end-of-life to live well until they die. We are delighted that this view is shared by the Oireachtas who passed the Assisted Decision-Making (Capacity) Act 2015 in December 2015. Under the provision of this legislation, an adult can make a legally binding statement (ACD) refusing any form of treatment, including life-sustaining treatment, if they lose capacity sometime in the future and they are unable to make treatment decisions for themselves.

We look forward to the implementation of this legislation and the positive impact it will have on many people living and dying in Ireland.

This paper is presented to inform the growing debate in Ireland. We understand the uncertainties surrounding advance care planning but also know of the growing support for dedicated efforts to support and enhance our approach toward advance care planning. As a leading driver of debate on dying death and bereavement in Ireland, we feel it is important to prompt debate on relevant areas and provide balanced input into these debates. We hope this paper does this.

Jean McKiernan

Chairperson, Irish Hospice Foundation
March 2016

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PREFACE

Perspectives of the Irish Hospice Foundation on Advance Care Planning and Advance Healthcare Directives.

1. The Context of this Perspectives Paper

This Perspectives Paper is the fourth in a series of documents published by the IHF, which address issues related to palliative and end-of-life care development and policy in Ireland. It considers the benefits of advance planning and the need for the citizens of Ireland to be supported to engage in advance planning for end-of-life, if that is their wish. This paper was informed by, and developed alongside, a number of different initiatives and work programmes instigated by the Irish Hospice Foundation (IHF) during the past six years: the National Council of the Forum on End-of-Life Care (*Forum*), the *Think Ahead* programme, and staff training programmes (e.g., *What Matters to Me; Final Journeys*). The paper was also informed by changes in legislation on assisted decision-making, which have now been passed and are awaiting enactment (Assisted Decision-Making (Capacity) Act, 2015).

In 2009, the IHF embarked on a year-long consultation with the Irish public, and launched the National Council of the Forum on End-of-Life Care (*Forum*). The report of the *Forum* supported the recommendation of the Law Reform Commission for legislation on advance healthcare directives (Law Reform Commission, 2009). The *Forum*'s report indicated that people were calling for increased dignity and respect for those approaching end-of-life, and for better end-of-life care to be available to all. This is a challenge the Irish Hospice Foundation has embraced fully in its vision and mission, where no one should face dying, death or bereavement without the support and care they need. Throughout the past four years, this commitment has led to sustained efforts from the *Forum* and the IHF, alongside other bodies, to advocate for the development of legislation to provide for advance healthcare directives, as envisaged by the Law Reform Commission.

One of the issues that emerged strongly from the submissions and feedback to the *Forum* was that the Irish public wanted some means of discussing and recording their preferences for end-of-life so that these could be followed should they ever be unable to communicate them. The public called for the implementation of core principles, such as dignity, respect, protection of autonomy and patient involvement enshrined in all approaches towards care at end-of-life, an approach best exemplified by palliative care. This led to the design of the IHF *Think Ahead* programme, a public awareness initiative that was launched by the IHF in 2011 to guide and empower people in discussing and recording their care preferences in the event that they cannot speak for themselves due to emergency, serious illness or death.

The Irish Hospice Foundation believes that advance planning for end-of-life is both a 'bottom-up' and a 'top-down' process. Thus, while the *Think Ahead* programme is perceived to be an essentially citizen-led initiative that has been designed to empower people to '*Think, Talk, Tell and Record*' their wishes for end-of-life, be they financial, legal, practical or directly associated with health and social care, the IHF also acknowledge that if these wishes are to be respected, a top-down approach is required to ensure that the necessary legal, medical and educational frameworks are in place. For this reason, we were heartened to see the new Assisted Decision-Making (Capacity) Act 2015

introduced, bringing greater clarity to this area and providing the policy framework to ensure planning for end-of-life becomes a more accepted part of a person's life. The role of the IHF to date has been to create a 'ripple' outwards, to start the Irish public thinking about what they want at the end-of-life. Over 40,000 Think Ahead forms have been requested and circulated to date, and the positive response from health professionals, civic society organisations, and members of the public around Ireland suggests that Think Ahead is meeting a real need. The tool is embedded in programmes, such as the Compassionate Communities Project in Limerick, which aims to develop more supportive community environments for those living with a serious life-threatening illness, those facing loss and those experiencing bereavement (McLoughlin et al., 2015).

In addition to the development of the *Think Ahead* programme, the IHF responded to the perceived need for good practice in communication at end-of-life by embarking on an ambitious programme of training healthcare providers in acute hospitals (*Final Journeys*¹), and more recently, in residential care settings (*What Matters to Me*²). These two training courses aimed to improve end-of-life care in acute hospitals and nursing homes, long-stay hospitals and older people's residential care settings by enhancing communication skills so staff at all levels are better able to engage in discussions with residents about what is really important to them. These one-day training programmes were immensely popular with over 4,000 individuals trained to date. Further training programmes have concentrated on enabling staff to work with families and GPs providing care in nursing homes. This training is likely to become more relevant with the introduction of codes of practice to support the new legislation.

1.2 Why this paper is important?

The IHF commissioned this paper for a number of reasons. First, advance planning is a very important subject that affects everyone, particularly people approaching end-of-life and those experiencing a future of significant diminished capacity. The paper indicates that relatively little empirical information has been published on the use, benefits and challenges associated with advance planning in an Irish context. Furthermore, the terminology surrounding advance planning is typically confined to the area of healthcare and it is often used in an inconsistent and ambiguous manner. We believe this paper will contribute to a clearer understanding of advance planning. Second, advance planning is increasingly and widely regarded as a worthwhile process, particularly in healthcare. This is acknowledged by legal and medical opinion, and the Oireachtas, which enacted the *Assisted Decision-Making (Capacity) Act, 2015* to replace the *Lunacy Act of 1871*. We feel that a balanced paper exploring the many facets of end-of-life planning is a worthy project. Third, the process of advance care planning is fraught with ethical issues, and expert opinion is currently divided on the mandatory use of advance health. We believe that the review of the ethical, legal and policy context of advance care planning in Chapter Three should provide an informative contribution to this debate.

1 <http://hospicefoundation.ie/education-training/staffdevelopment/final-journeys>

2 <http://hospicefoundation.ie/education-training/staffdevelopment/what-matters-to-me>

1.3 What is the review telling us?

The review of the advance planning landscape in Ireland, by Weafer and Murphy, is interesting, and informative, and it provides a good ‘stock-take’ of where Ireland sits regarding advance healthcare planning and specifically, advance healthcare directives. Firstly, the authors tell us that there is a growing body of research on advance care planning and advance healthcare directives but that the terms are often used interchangeably, when, in reality, they are two related but different concepts. The authors note that advance care planning is widely accepted as being ‘a good thing’ and there seems to be little debate on this. The literature suggests that good advance care planning results in better care decisions, especially at end-of-life. However, while every healthcare provider caring for persons with life-limiting illness should be able to engage in this process, the IHF experiences tell us that many healthcare staff are not prepared, and that there are many training gaps in communication skills and in these discussions. Without careful attention to staff training/capacity building we cannot expect staff to have capacity in the critical conversations that support proper advance healthcare planning.

The most substantive debate is around the value of advance healthcare directives, a process whereby a person notes what medical care is NOT to be administered if they become incapacitated. In Chapter Three on the ethical, legal and policy context of advance care planning and advance healthcare directives in Ireland, Dr John Weafer and his colleague Sarah Murphy note that there is a growing drive towards legitimisation and recognition of advance care directives coming from a legal and human rights perspective. *The Assisted Decision-Making (Capacity) Act* passed in December 2015 represents a significant endorsement of advance healthcare directives in Ireland. In exploring some of the challenges regarding advance healthcare directives, it seems from the literature that the debate on their value is not due to them being considered inherently wrong but stems more from:

- a professional uncertainty as to how to support and integrate them into the care of all adults, and particularly vulnerable adults, which is partly driven by confusion over their legal status and confusion in terminology
- a general reluctance in society to discuss death and dying which prevents care staff engaging in discussions on death and dying with patients, and
- a low awareness of how advance care planning and advance healthcare directives can help a person achieve autonomy at end of life, and indeed the importance of including autonomy as a consideration when facilitating decision making.

It is likely that some element of these different factors impact on advance care planning discussions, and the systems for advance care directives. Given these terms are poorly separated in the literature, there remains confusion in research findings as to the value of advance care planning and advance healthcare directives.

Another theme running through the literature is that of ‘medical paternalism’, where a doctor’s belief and desire to do the best for their patient, alongside a professional belief that they understand the nature and trajectory of serious illness better than patients themselves, results in discomfiture with patients making their own healthcare decisions. In effect, this paternalism competes directly with the concept of citizen autonomy. Most healthcare directives do advise that a doctor be consulted so as to ensure all healthcare issues are understood (as does Think Ahead), but this is not necessary for a directive to be legally recognised. At a recent international colloquium on Palliative Care, held in Dublin, Professor Lucas Radbruch, an eminent palliative care consultant, noted:

“When I was sixteen, my parents told me what to wear and where to go – there is little chance I would be able to do that with my sixteen year old daughter today – citizen autonomy has radically increased and is likely to increase further - as medical professionals we need to be ready for this”.

The paper indicates that the uptake of advance care directives is still very low in many countries where they are legal. We are not sure why this is so. It may be that some people do not want to record an absolute healthcare directive but are happy with discussion on options only. Alternatively, it may be due to low awareness or perhaps death anxiety, which is a key barrier to advance healthcare planning and directives. The review also demonstrates that more public engagement is required to create greater acceptance and understanding of the need to consider what it is we want for ourselves and our loved ones at end-of-life.

These questions challenge us all to decide where we should focus our energies and resources. If the public reluctance to engage in debate on dying, death and bereavement, or to follow through with advance care planning, is due to death anxiety, increased efforts at public debate may yield limited returns in changing public behaviour. While increased public debate and engagement may increase awareness of advance care planning and end-of-life issues, more fundamental change in public behaviour will take much longer, given the need to change how we approach end-of-life as a society. Countries, such as the UK, with their national programme, *Dying Matters*, are useful examples of how this is being approached elsewhere. HIQA has been driving the end-of-life care agenda since 2009 ((HIQA), 2008 Standard 16, p.23) and this is resulting in more attention being paid to recording advance care planning decisions and advance healthcare directives. Certainly the enactment of national legislation will provide a legal and policy framework, in line with international law, to support advance care directives and drive change. Once the legislation is implemented, much more can be done to use ‘policy hooks’ to strengthen the State response to support planning for end of life.

It is clear, from our own work with healthcare staff and the implications of the new legislation, that training of healthcare staff will be required if we are to enable staff support good end-of-life healthcare planning and to engage with advance healthcare directives. It seems unreasonable to expect these professionals who may have had very little training themselves to suddenly be able to engage in discussion on dying death and bereavement with their patients. Our experience is that there is little ‘system readiness’ for the introduction and implementation of advance healthcare directives, and without attention to training, it will be very slow to change. We are all aware of clumsy conversations on sensitive issues that cause great hurt and offence. Equally we are aware of cases where sensitive discussions do not take place so as to avoid dealing with these issues. We know there is confusion concerning the use and legal status of advance healthcare directives, and this can only be overcome by providing training and facilitating debate. This training should be experiential, reaching into core values and culture and supported by culture change in the healthcare setting. This type of change cannot be achieved by dictate from on high! Finally, it needs to be owned and driven from within the healthcare system, so that this training is deemed important and valued within that system. Our training programmes, which enable staff to feel more comfortable in having discussions on end-of-life, have been well received and they have been evaluated (both internally and externally) very positively. We intend to continue to roll out and adapt this training to meet needs. We would expect to see clear training strategies set for those professionals providing care to persons with serious illness or nearing end-of-life covering these issues. The forthcoming code of practice will drive this training but training needs to be resourced, staff need to be released and quality needs to be assured.

1.4 What have we learned to date on our engagement?

Engagement in dying, death and bereavement is widely welcomed in Irish society. From our work to date, and specifically through our recent work on the public Forum and with *Think Ahead*, we know there is a very receptive audience to discussions on end-of-life. As previously mentioned, more than 40,000 Think Ahead forms have been distributed to the public and members of civic organisations. This positive response is replicated by work currently underway in the Milford Care Centre's Compassionate Communities Project (McLoughlin and Rhatigan, 2016). We believe that, with good planning, simple messages and informed resources, people will engage and discuss dying, death and bereavement. Conversely, there is not a universal openness to discussions on dying, death and bereavement and often the subject is avoided in the media and public debate. As Dr Weafer notes, there is a general 'death denial' in society, which inhibits people engaging more with dying, death and bereavement, especially when it impacts on an individual's personal life. However, it is clear, not only from our own work, but also from international campaigns on sensitive subjects, that more can be done to engage the public and create more dialogue on end-of-life issues. I liken this debate to discussions on breast cancer, where, 30 years ago, women did not discuss the 'big C' and they were reluctant to approach their doctor with concerns. As a result, breast cancers were detected much later with poorer outcomes and women were left unsupported and lonely with few to talk to about their illness and experiences. As a society, we have managed to change this approach and today there is far greater openness and support for women (and men) with cancer.

Dying death and bereavement is not just about health

Many of the issues raised in the *Forum* consultation were concerned with healthcare. However, other topics also emerged that stretched beyond health to include legal, environmental and financial issues, social care, dignity, compassion in society and spiritual care. This work is replicated in a study undertaken by Senator Marie Louise O'Donnell for An Taoiseach, Enda Kenny, on how civil servants deal with dying, death and bereavement among its own members (Marie Louise O'Donnell, 2015). Death is universal and having a good death is determined by many factors, not only by the healthcare you receive but also by the social, family and state supports which we interact with throughout our lives.

The growing appetite for Think Ahead by NGOs and civic organisations

There is a growing appetite for *Think Ahead* from individuals, civic organisations and international groups. In addition to more than 80 presentations to civic organisations around the country, IHF staff have presented information posters at national and international conferences, and contributed to diverse articles. At the launch of *Think Ahead* in 2014, An Taoiseach, Enda Kenny said:

“The Think Ahead initiative helps prevent shock, helps avoid confusion...by encouraging us to think, talk and tell....It takes the attention, the intention and desire of the way we live and applies them equally and exquisitely to our death and dying, so we have some control, choice, peace, dignity at the end.”

The very successful levels of engagement with NGOs and civic organisations achieved by the *Think Ahead* programme challenges the IHF to think about how we, as an organisation, engage with NGO and civic organisations on all aspects of dying, death and bereavement. We know more can be done to achieve the best care at end-of-life for all, to support planning for end-of-life and to support those left bereaved, but can we build a coalition of grassroots organisations to support us in our work? This has been identified as a core objective in our new strategy.

1.5 Where to next for the IHF?

As an organisation entering a new strategic cycle, this review is very timely. We plan to mainstream the *Think Ahead* programme into our suite of public engagement programmes in 2016. It has proved its worth and needs to move from a pilot stage into a core part of our activities. This means we will review our approach towards public and civic engagement across the organisation, so as to develop a stronger relationship with public and civic groups across the country.

However, there is a programme of work, specific to the agenda around advance healthcare directives that still needs to be addressed. Accordingly, we intend to:

- Seek inter-agency and government support for advance healthcare planning. These initiatives will require investment and we believe that some State investment is warranted in supporting citizens on advance care planning and in advance healthcare directives.
- Continue to advocate for the development of a strong code of practice led by the Department of Health.
- Further develop our suite of programmes to facilitate more public engagement and public debate on end-of-life care, advance healthcare directives and advance care planning based on the new legislation.
- Embed the Think Ahead tool in the approaches used by other organisations and NGOs who use the tool as part of their work.
- Develop an online platform for completing and storing the Think Ahead form in partnership with Patients Know Best (www.patientsknowbest.com).
- Continue to adapt our training programme so as to provide support and training to healthcare staff regarding communication skills on advance care planning and advance care directives.
- Evaluate the social impact of our activities so as to ensure investment is directed in the right way.
- Continue to advocate for better palliative care services - a core component to enable best care at end-of-life.

In drawing this preface to a conclusion, it seems wise to note the rising number of older persons – from current projections, the older population (i.e. those aged 65 years and over) is projected to increase very significantly from its 2011 level of 532,000 to approximately 1.4 million by 2046. The very old population (i.e. those aged 80 years of age and over) is set to rise even more dramatically, increasing from 128,000 in 2011 to approximately 480,000 in 2046. The average annual number of deaths is projected to increase steadily from the 2011 figure of 29,000 to an annual average of 48,000 in the period 2041- 2046. (Sources CSO, 2015). This means there will be an increasing need to support people at end-of-life, to become better prepared as a health service to provide excellent end-of-life care, and to be better able to support decision-making for those nearing end of life or with serious illness. As patient autonomy grows this demand for inclusion in decision-making will come more and more from citizens. Finally, the research report is telling us that we need to continually evaluate our efforts and to link these efforts to patients receiving better care at end-of-life, to include dignity, respect and autonomy.

Concluding statement

We believe that planning ahead is important for anyone, regardless of whether they have an illness or not. None of us can say for sure whether we will always be able to make our own decisions about our care. The IHF actively supports the notion of advance planning as a choice and an important aspect of personal autonomy as well as a key aspect of public policy. It is important that people understand advance care planning and advance healthcare directives, and their right to refuse treatment, if they so wish. We concur with the recommendations of a recent report published in Wales on Advance Decisions to Refuse Treatment (ADRTs) (Kitzinger and Kitzinger, 2016).

- Public education, media engagement and cultural events to encourage people to plan for potential loss of capacity;
- De-bunking the myth that ‘next of kin’ have decision-making powers to change an advance decision, be it legal, financial or health related;
- Facilitating access to well-designed forms, guidance and skilled support.
- Normalising Advance Decisions to Refuse Treatment.
- Training relevant practitioners to ensure they understand what ADRTs are, so that they can provide appropriate guidance or referral, and can act in accordance with the law concerning them.

We have championed the development of a tool to facilitate advance planning - Think Ahead. However, we recognise that there is uncertainty and fear about advance healthcare directives and we feel it is important and our duty to prompt debate and discussion through this paper. The field is expanding and where there were few papers a few years ago, there is now an evolving wealth of information. It will be informed by other IHF work concerning dementia and end-of-life care.

We hope that a public health approach towards planning for end-of-life care can ensure that each person has the dignity and autonomy they desire at end-of-life. We believe this paper is both timely and worthwhile, and we hope it will generate informed debate on a very important aspect of Irish life.

Sharon Foley, CEO, Irish Hospice Foundation

GLOSSARY

1) Advance Care Planning

Advance care planning refers to a process of discussion and reflection about goals, values and preferences for future care in the context of an anticipated deterioration in a person's condition with loss of capacity to make decisions and communicate these to others. (A)

2) Advance Healthcare Directive

An Advance Healthcare Directive is an expression made by a person who has capacity (in writing, to include voice, video recording and speech recognition technologies) of their will and preferences concerning specific treatment decisions in the context of an anticipated deterioration in their condition with loss of decision-making capacity to make these decisions, to give consent to or to refuse treatment and communicate them to others. An advance healthcare directive is legally binding (therefore certain formalities must be followed) when a person writes down what treatments they would refuse in the future and the circumstances in which the refusal is intended to apply. The ADMC Act 2015 provides that a request for specific treatment is not legally binding but should be followed if relevant to the medical condition for which treatment is required. (B)

3) Decision-Making Capacity

Decision-making capacity is the ability of a person to understand at the time a decision is to be made, the nature and consequences of the decision in the context of the available choices at that time. This means that decision-making is time and issue specific. Every adult is presumed to have capacity to make decisions about their own healthcare; this is enabled by focusing on the person's will, preferences, beliefs and values; addressing both their autonomy and protection. (B,C)

4) Enduring Power of Attorney

An Enduring Power of Attorney (EPA) is a document, drawn up with a person who has decision-making capacity, which gives another person(s) the power to make general and/or specific decisions. This comes into effect when a person lacks decision-making capacity and their enduring power is registered with the Wards of Court Office.³ (B,D)

5) Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (E)

³ Note that under the 1996 Act the EPA can be registered when the 'person is or is becoming incapable'. In the 2015 Act, the EPA can only be registered when the person lacks decision-making capacity.

References

- A. The Palliative Care Programme Health Service Executive. Glossary of Terms [Internet]. Health Service Executive (HSE); 2012. Available from: <http://www.hse.ie/eng/about/Who/clinical/natclinprog/palliativecareprogramme/Resources/glossary.pdf>
- B. Oireachtas. Assisted Decision Making (Capacity) Act [Internet]. Oireachtas; 2015. Available from: <http://www.oireachtas.ie/documents/bills28/acts/2015/a6415.pdf>
- C. Medical Council (Ireland). Guide to Professional Conduct and Ethics for Registered Medical Practitioners [Internet]. Medical Council; 2009. Available from: <https://www.medicalcouncil.ie/Newsand-Publications/Publications/Information-for-Doctors/Guide-to-Professional-Conduct-and-Ethics-for-Registered-Medical-Practitioners.pdf>
- D. McCarthy J, Donnelly M, Dooley D, Louise C, David S. End-of-Life Care. Ethics and the Law. Cork: Cork University Press; 2011
- E. World Health Organisation. WHO Definition of Palliative Care [Internet]. World Health Organisation; 2016. Available from: <http://www.who.int/cancer/palliative/definition/en/>

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CHAPTER ONE: INTRODUCTION

1.1 Background

Death is part of the life cycle and each year approximately 30,000 people die in the Republic of Ireland.⁴ However, life expectancy has increased significantly in Ireland during the past 100 years or so,⁵ and more people are living longer than was possible in previous generations, due to technological and medical advances, and improvements in the quality of healthcare. Furthermore, the quality of death in Ireland is amongst the highest in the world (Economist Intelligence Unit, 2015)⁶. However, death is inevitable and it can also be traumatic, with many people dying in difficult circumstances they may not have wanted or foreseen, such as chronic illness, poverty, loneliness, abuse and neglect (Naughton et al., 2010, Walsh and Harvey, 2011, Weafer, 2014a). Furthermore, while most Irish people would prefer to die at home rather than in hospital (Weafer, 2014c),⁷ the reality is that most people die in hospital (McKeown, 2014).⁸ A similar preference for home deaths has also been recorded in other countries, including the US (Gruneir et al., 2007) and the UK (Demos, 2013, NatGen, 2013). Furthermore, while most Irish adults would like to die surrounded by their loved ones in familiar surroundings and being free from pain (Weafer, 2014c), unfortunately, death does not always occur in this way (O'Mahony-Browne Research Consultants, 2005). Many people living today will have to cope with one or more chronic conditions for an extended period of time,⁹ or spend some years living with disabilities, (functional and/or cognitive impairment) at the end of life (Weafer, 2014a).

4 Just over 30,000 deaths were registered in the Republic of Ireland in 2013 (www.cso.ie).

5 Life expectancy has increased significantly since the foundation of the Irish state. In 1926, life expectancy for Irish males and females was 57 years. By 2010, male life expectancy had increased to 78 years and female life expectancy had increased to 83 years (www.cso.ie). Conversely, it is also a society where people in lower socio-economic groups are more likely to experience chronic ill health and die earlier than those who are more advantaged (www.publichealth.ie).

6 Ireland ranked 4th in the Economist Quality of Death worldwide index.

7 The IHF 2014 national study found that 74% of Irish adults would prefer to be cared for at home if they were dying, compared with just 5% who would prefer to be cared for in a hospital.

8 Data collected by the HSE estimated that 43% of deaths in Ireland in 2010 occurred in a hospital, compared with 26% of home deaths.

9 Data published by the Central Statistics Office (CSO) indicated that 32% of people who died in 2003 died from circulatory diseases (e.g., heart attack), 29% died from cancer, 12% from a respiratory disease (e.g., lung disease) and the remainder (27%) from a range of other causes.

Most Irish adults have direct experience of bereavement following the death of a loved one (Weafer, 2014c, Amárach Research, 2011).¹⁰ However, for many Irish people, death is a taboo subject, ‘the ultimate mystery, unimaginable yet inevitable, a human universal’ (Van Doorslaer and Keegan, 2001, p.4). Research and informed opinion suggests that while people are willing to engage in general discussions around death and dying, they are reluctant to discuss the more personal details of death (Weafer, 2014c, Ipsos MORI, 2010, Solomon et al., 2015). In the words of Mrs Justice Catherine McGuinness, Chair of the National Council of the Forum on End of Life in Ireland, an initiative of The Irish Hospice Foundation:

‘Young people don’t think about death. Middle age ignores it. There are things to look forward to – starting a family, buying a house, retirement. The reality is we never know what is around the corner. As sure as we have been born, we will die, and we have to stop turning a blind eye to this fact of life’.

(www.hospicefoundation.ie)

However, some commentators believe that death need not be such a taboo if people are facilitated to face the ‘terror’ of ‘the dark side’ of death through open discussion (Vail et al., 2012, Bhatnagar and Joshi, 2012). The IHF believes that planning ahead for end-of-life is an important part of this process and they have produced a number of resources to help people plan ahead¹¹ (Irish Hospice Foundation, 2015).

Advance Planning

This paper is concerned with the concept and practice of advance planning, incorporating advance care planning and advance healthcare directives. The notion of advance planning is a very broad concept, and although it is most closely associated with healthcare in the literature, advance planning is ‘wider than simply health care and ‘there is a myriad of financial, legal, social, cultural and administrative issues related to a person’s wishes other than those related directly to health care’ (Patricia Rickard Clarke, 2013, p.15). Advance planning typically takes place when a person encounters life-changing circumstances, sometimes when they are healthy and well, and sometimes when facing illness.

The Irish Hospice Foundation (IHF) actively supports the notion of advance planning for end-of-life as an important personal decision and a key aspect of public policy. In this regard, the Forum on End-of-Life (*Forum*) in Ireland was established by the IHF in 2009. The *Forum* is aimed at awareness-raising, planning and promoting public debate on issues relating to dying, death, and bereavement in Ireland (Irish Hospice Foundation and National Council of the Forum on End of Life in Ireland, 2013). The IHF and the *Forum* subsequently launched the *Think Ahead* programme in 2011, a public awareness initiative that was designed to facilitate the Irish public to discuss and record their preferences for end-of-life (See chapter six for further information on the Forum and the Think Ahead programme). The IHF has also advocated for the enactment of legislation to support the introduction of advance healthcare directives, and in the development of various tools and guidelines that will assist people with dementia to plan for end-of-life through its *Changing Minds* Programme.¹²

10 Research commissioned by the Irish Hospice Foundation (IHF) found that just over half (53%) of Irish adults interviewed in a national, statistically representative study said that they had experienced the death of someone close to them during the previous two years (Weafer, 2014). An earlier IHF study by Amárach Research (2011) found that over four in ten Irish adults had lost someone close to them in the last two years and that over eight in ten Irish adults had lost someone close to them at some stage in their lives.

11 See for example, the IHF Think Ahead programme and the *End-of-Life Care Toolkit*, compiled by the IHF for staff working in residential care centres for older people

12 The aim of the *Changing Mind’s* programme is to enable more older people, particularly those with dementia, to live and to die with dignity at home or in residential care settings.

This paper seeks to identify and examine contemporary policy and legal developments surrounding the concept of advance planning, including empirical research, and to inform and shape further IHF developments in this area.

Planning Ahead in Ireland

Ireland's socio-economic landscape has changed significantly during the past fifty years, with the result that Ireland has become a more modern, urban, cosmopolitan, educated, mobile and secular society (Murphy, 2000). It is a country that has experienced 'seismic changes in the socio-cultural and political sphere such as the digitalisation of society, a collapse of mass faith in organised religion, a faltering of established community values, the neo-liberalisation of state policies and work cultures, and the cynicism of an increasingly postmodern society and culture' (Haughton, 2014, p.374). It is also a society where Irish citizens are increasingly obliged to make sense of their worlds by making personal choices and planning for an uncertain future. In essence, life has become 'a planning project' as people seek 'to bring their future under control' (Beck-Gernsheim, 2002, p.43).

Thus, while the nature and timing of our deaths is not always predictable, it is possible for a person to influence certain aspects of their end-of-life journey, through diverse forms of advance planning. For example, in most countries people are actively encouraged to plan for retirement by taking out a pension, or to make provision for their deaths by making a will. Similarly, in the context of healthcare, people are increasingly being encouraged to plan for their future healthcare by recording their preferences for how they would like to be cared for if they were hospitalised, or what they would like to happen to them after they die.¹³ However, while it would appear to make sense to plan for unforeseen circumstances that may arise, if we want to make our wishes known and ultimately respected, most people living in Ireland have been reluctant to engage in any form of advance planning that would make provision for their old age or death (Weafer, 2014c). Some of the reasons for this lack of engagement in advance planning will be explored in chapter five.

13 Initiatives, such as the IHF 'Think Ahead' programme are designed to empower people to 'Think, Talk, Tell, Record and Review' their wishes for end-of-life, be they financial, legal, practical or directly associated with health and social care (See chapter six).

1.2 Research questions

This Perspectives Paper, the fourth in a series published by the Irish Hospice Foundation,¹⁴ considers the benefits of advance planning and the need for the citizens of Ireland to be supported to engage in advance planning for end of life, if that is their wish. The paper will address the following questions within the context of end-of-life:

1. First, what does advance planning entail?
2. Second, how is advance planning currently regarded in legal, ethical and policy contexts?
3. Third, what is the rationale for advance planning?
4. Fourth, what are the main drivers and barriers of advance planning?
5. Fifth, what is the current response of the Irish Hospice Foundation to the issues raised in this paper?

1.3 Methodology

This paper is based on a literature review that used a combination of key search words ('advance planning', 'advance care', 'advance directives', 'advance healthcare directive', 'barriers', 'enablers', 'advantages' and 'disadvantages') to conduct a search of selected social/medical databases, including EBESCO, Applied Social Sciences Abstracts, Academic Search, JSTOR, and PubMed. The primary purpose of the literature review was to identify the major themes related to advance planning. A number of the articles cited in the paper are systematic reviews of particular aspects of advance planning, such as the use of advance care planning in dementia. The database search was supplemented by a separate review of a range of prominent Irish and international journals. Given the shortage of empirical research in this area, it was also decided to include narrative material from non-peer reviewed sources, such as clinicians and advocates for advocacy.

1.4 Structure of the paper

Following this introduction, chapter two will briefly introduce the concept and terminology of advance planning. Chapter three will review the main ethical, legal and policy factors underpinning advance care planning in Ireland. This is followed in chapter four by a discussion of the rationale for advance planning. In chapter five, the main drivers and barriers to advance planning are summarised. The IHF Think Ahead programme is reviewed in chapter six. The response of the Irish Hospice Foundation to the issues raised in this paper is outlined in the Preface to the paper. Finally, a copy of the Think Ahead form is appended to the paper.

¹⁴ The previous three Perspectives Papers published by the IHF dealt with the related topics of palliative care, access to specialist care services, and place of death.

CHAPTER TWO: THE TERMINOLOGY AND SCOPE OF ADVANCE PLANNING, ADVANCE CARE PLANNING AND ADVANCE HEALTHCARE DIRECTIVES

2.1 Introduction

The aim of this chapter is to introduce the concept and terminology of advance planning. We live in an uncertain world, where the unexpected can happen, and often does. For some people, this uncertainty is compounded by issues such as pension insecurity (Moloney and Whelan, 2009, Friends First, 2011), poor health (Department of Health, 2014), changing attitudes and values (Weafer, 2014b), and elder abuse and neglect (Naughton et al., 2010). Accordingly, planning ahead for an uncertain future makes sense from a number of different perspectives. Within the context of healthcare, advance planning allows for patients to have a greater opportunity to plan their healthcare, and to ensure that their end-of-life preferences are known and recorded (McCarthy et al., 2011). This is particularly the case for patients with diminished mental or physical capacity, where planning ahead is increasingly considered to be a critical aspect of end-of-life care (MacConville, 2011, Weafer, 2014a). Similarly, making a will can avoid confusion and possible strife around a person's preferences for their assets after their death.

2.2 Advance Planning

Advance planning (AP) refers to a broad range of decision-making activities that relate to end-of-life. It is essentially a mechanism that encourages and makes provision for people to consider, amongst other things, issues associated with healthcare, finances, administration, legal matters, and what happens to their body after death, such as organ donation or planning funeral arrangements. A recent review of the consumer experience by *Which* magazine in 2015 (Which? 2015) identified three stages to the dying process from the perspective of consumers (Figure 2.1, overleaf).

Figure 2.1 Advance Planning as a Process

| BEFORE (‘Rest’ of Life Planning) | DURING The end of life (terminal diagnosis/advance old age) | AFTER (Bereavement) |
|---|---|--|
| Making a will | Accessing and managing care and support | Dealing with loss |
| Advance decision | Communicating with healthcare professionals | Organising and paying for a funeral |
| Estate management | Accessing finance (insurance and benefits) | Probate |
| Lasting Power of attorney | Managing up-front costs | Estate administration |
| Protection products (e.g., life assurance). | Funeral planning | Re-enablement (e.g., returning to work, re-accessing social networks). |
| Funeral insurance | | |
| Financial advice | | |

Source: Dying Better. The consumer experience at the end of life. Which? Consumer Insight, February 2015.

Advance planning is generally regarded as a process, rather than a once-off event, which enables the person to ensure that their wishes, values and preferences are heard and understood, in the event that they may become unable to speak for themselves. It is a process, that should allow for people sufficient opportunity to make decisions to refuse certain treatments and to change their minds in future (Barnes et al., 2007). Advance planning in itself, is not a new concept and it is increasingly regarded as a well-recognised part of good civil development. For example, public campaigns have been used more or less successfully to motivate people to make wills (MyLegacy, 2012);¹⁵ to have greater awareness of, and to have regular medical check-ups for different forms of cancer and heart disease; to wear a seat belt when in a car; and to stop smoking in public places.

¹⁵ The ‘Best Will in the World’ Week is organised by MyLegacy.ie to encourage people to make wills and leave donations to charities. However, a survey commissioned by MyLegacy, a coalition of over 80 Irish charities, in 2012 showed that only 34% of people living in Ireland have made a will. This figure changed according to age: 51% of people aged between 45 and 64 years have made a will, compared with 82% of those over 65 years of age.

While some of these campaigns have been successful because they were supported by legal enforcement and underpinned by health psychology models, such as the smoking ban, others have depended on a change in the mindset of the Irish public when confronted with empirical evidence showing the potential consequences of their personal behaviour if they did not change their behaviour. The seatbelt campaign is a good example of how a combination of legal enforcement, advertising, and public pressure has changed public behaviour in Ireland. However, in the absence of one or more of these cornerstones of change, it is very difficult to see how widespread behavioural change could be achieved.

2.3 Advance Care Planning (ACP)

Advance care planning (ACP) is essentially about healthcare. It refers to ‘a process of discussion and reflection about goals, values and preferences for future treatment in the context of an anticipated deterioration in the patient’s condition with loss of capacity to make decisions and communicate these to others (Royal College of Physicians of Ireland, 2014, p.3). The emphasis on care is also apparent in the definition used by the Hospice Friendly Hospitals programme of the IHF in its *Quality Standards for End of Life Care in Hospitals*, which defines advance care planning as the process of discussion between a person and their carer, and often those close to them, about future care (Irish Hospice Foundation, 2010, p.82). ACP entails clarifying a patient’s understanding of their illness and the treatment options that are available to them in the context of their values and expectations. Advanced care planning usually takes place when there is a known illness and further deterioration in the patient’s condition is anticipated. However, this is not necessarily always the case. The process of discussion, choice and clarification of a patient’s medical values and goals can start at any time and be revisited periodically, but it generally becomes more focused as the patient’s health status changes (Institute of Medicine, 2014).

2.4 Advance Healthcare Directives (AHD)

An Advance Healthcare Directive (AHD) may be defined as a ‘broad term encompassing several types of patient-initiated documents, especially living wills and proxy statements’ (Institute of Medicine, 2014). In Ireland, it is used ‘to describe an advanced expression of wishes by a person at a time when they have the capacity to express their wishes about certain treatment that might arise at a future time when they no longer have capacity to express their wishes’ (Law Reform Commission, 2009, p.2). AHDs are not intended to be a static, unchanging document. Rather, the use of AHDs represents a process whereby a patient’s changing preferences for end-of-life are recorded as they face a progressive disease.

Advance healthcare directives are a relatively recent phenomenon in Western society and there is little published material on this topic in Ireland. However, they are increasingly used in many countries, such as Australia, Canada, the USA, and the UK, to ensure that the wishes of a patient are known and respected even if they lose capacity to make their own treatment decisions. The US was the first country to formalise the concept of a ‘living will’ in the late 1960s, and in 1976, California was the first state legally to sanction advance directives in the form of living wills. The concept of a ‘living will’ was subsequently embedded into US legislation through the *Patient Self-Determination Act* (1991), which affirms patients’ rights in decision making at end-of-life by requiring health care institutions to inform patients of their rights to refuse or discontinue treatment.

Advance healthcare directives are recognised by law in many countries, including Ireland. The practice is usually underpinned by relevant legislation, such as the *Mental Capacity Act* (2005) in the UK, and the *Australian National Framework for Advance Care Directives* (2011). Ireland enacted the *Assisted Decision-Making Act, 2015* in December 2015. It is intended that different parts of the Act will come into operation at various stages commencing in 2016.

2.5 Terminology of healthcare planning

The terminology surrounding advance care planning is often inconsistent in the way it is used by researchers, academics, legislators and policy-makers. This is understandable, perhaps, since the emphasis of advance care planning has evolved over the years when it was first introduced as a formalised concept, from an emphasis on ‘the completion of written directives, such as advance directives’ to a contemporary focus both on ‘the completion of written forms’ and also on the ‘social process’ (Brinkman-Stoppelenburg et al., 2014). Within the context of healthcare, the literature refers to both advance care planning and advance healthcare directives, where advance healthcare directives constitute a specific form of advance care planning. Others use the terms interchangeably. For example, Gillick believes that advance healthcare directives are ‘the cornerstone of advance planning’ because they ‘encompass both instructions about what kind of care should be provided (living wills) and who should make the decisions (proxy designations) (Gillick, 2004, p.7).

The terminology of advance planning is ambiguous and inconsistent, particularly in the area of healthcare, where commentators often use advance care planning and advance healthcare directives interchangeably. Research from residential care settings suggests that when conversations about future care take place, they are not usually recorded as an advance care plan (Planning for the Future, HSE, 2013). This paper argues that there is a tangible difference between the different forms of advance care planning and that this difference is reflected in the way and frequency with which they are used in healthcare settings (figure 2.2 on page 22).

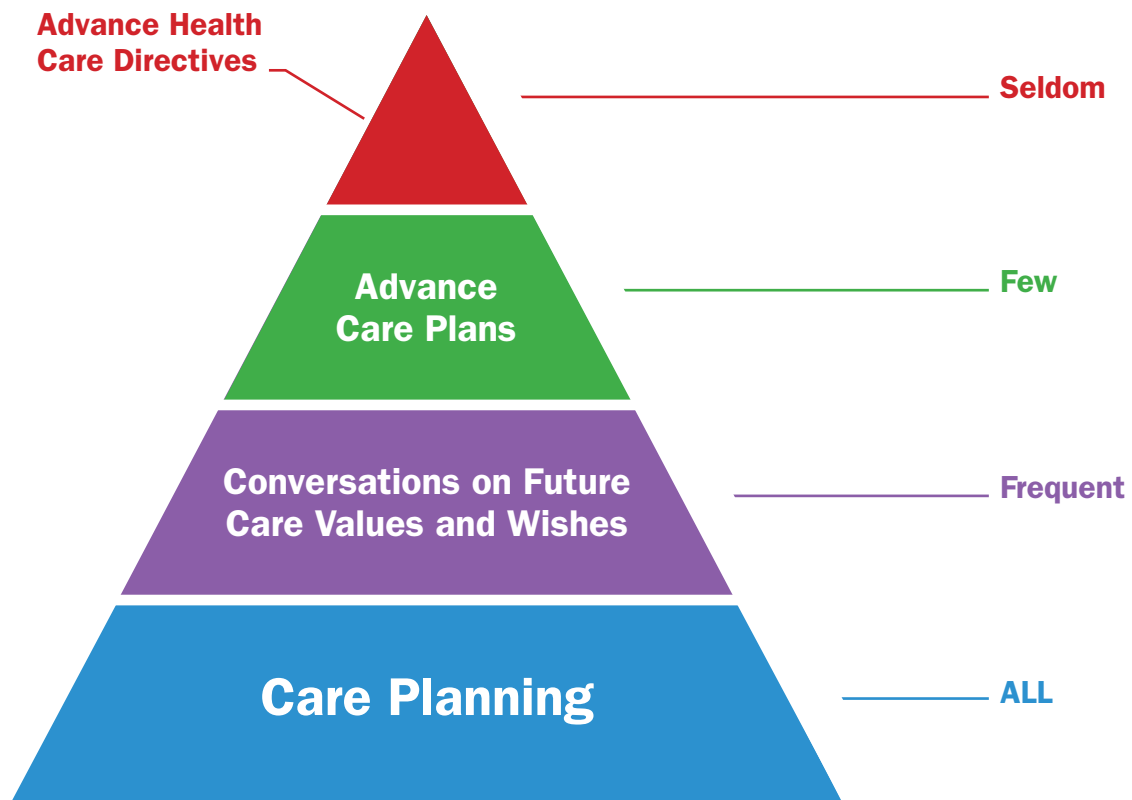


Figure 2.2 End-of-life Care/Advance Care Planning in Health Care Settings

All patients have care plans and conversations take place about a patient’s future preferences and wishes. However, while these are sometimes translated into advance care plans, this does not always happen. It is also argued that advance healthcare directives are rarely seen in healthcare settings. This inconsistency in record keeping compounds the difficulty for the views and wishes to be identified and acted upon. For the purposes of this paper, advance care planning will refer to the generic process of care planning, while advance healthcare directives constitute a specific form of advance care planning, whereby direction is given as to a patient’s preferred medical treatment.

CHAPTER THREE: THE ETHICAL, LEGAL AND POLICY CONTEXT OF ADVANCE CARE PLANNING IN IRELAND¹⁶

3.1 Introduction

People are living longer in Ireland due to a variety of factors, including advances in medical technology and improvement in the quality of care given to patients. Although welcome, this trend can present challenges to healthcare decision-making about the end of life (Waldrop and Meeker, 2012). Some commentators in the US and elsewhere believe that end-of-life care is a potential 'looming health crisis' because of the demographic shift to older adults, the enormous healthcare costs consumed in end-of-life care, and complex ethical issues (Morhaim and Pollack, 2013, p.8). Very ill people can now be kept alive in ways that were not previously possible, such as with the support of artificial ventilation and PEG feeding. This can lead to ethical issues and uncertainty regarding people's wishes, particularly when the patient's capacity has deteriorated to an extent that they cannot make an informed decision on their treatment. Issues also arise when legislation governing individual rights is outdated, when there is a lack of awareness regarding the law, or when policy does not meet international obligations. In order to better understand the development of advance care planning and advance healthcare directives in Ireland, the ethical, legal and policy context of advance care planning is briefly outlined below.

3.2 Ethics

The primary purpose of ethics is to 'consider theories about what human beings are capable of doing, alongside accounts of what they ought to do if they are to live an ethically good life' (McCarthy et al., 2011, p.24). Rather than dealing in certainties, ethics entails a process of negotiation whereby people are given 'tools for thinking about difficult problems' (McCarthy et al., 2011, p.14). The process of advance care planning is 'a broad continuum of activities that can be fraught with ethical issues', such as knowing when to initiate ACP and what role a care provider should take in the process (Baughman et al., 2014, p.53). In order to understand these issues, the following section will explore the ethical-legal principles of informed consent, capacity, and patient autonomy, which underpin advance care planning/advance healthcare directives.¹⁷

16 Unless otherwise stated, any reference to advance care planning in this chapter will also include advance healthcare directives.

17 See McCarthy (2011) for a detailed review of end of end-of-life care ethics and the law.

3.2.1 Informed consent

The requirement of informed consent to treatment and care is intended to minimise harm, maximise benefit and respect autonomy. Informed consent presupposes voluntariness, information, and capacity (McCarthy et al., 2011). Informed consent occurs when a competent and informed person, understanding the risks and benefits at stake, voluntarily and intentionally either gives permission to a health care professional or refuses a health care professional permission to treat them for their condition. McCarthy suggests that there are professional responsibilities required to facilitate an informed consent process: assessing capacity in a way that is fair and free from prejudices; facilitating people with borderline capacity; addressing broader issues of communication by listening and speaking, understanding the emotional and social context, and providing honest advice; and considering consent (and refusal) as a process of repeated engagement. Informed consent is not a once-off event.

3.2.2 Capacity

Irish law upholds a presumption of capacity unless the contrary is clearly indicated. Measuring capacity is complex, difficult and uncertain, partly because capacity can fluctuate. One approach¹⁸ to assessing capacity, the functional approach,¹⁹ focuses on the individual's ability to perform the task of understanding and deliberating on the particular health-care decision being made at the time the decision has to be made. The functional test determines if the individual is free (uncoerced), able to understand a therapeutic procedure, able to deliberate on its benefits and risks in light of their own values and desires, and able to communicate their wishes through verbal and non-verbal means e.g., talking, sign language etc. In a situation where a person has lost capacity, health professionals have ethical responsibility for deciding on the best clinical approach to their care, taking into account the person's will and preferences. They should do this on the basis of any existing advance directive²⁰/ power of attorney,²¹ substituted judgement standard,²² or best interests standard.²³

18 There is a problem at present in that there not a standard approach to assessing capacity. The status model is still being used in some cases, even though the Medical Council guide and the HSE Consent Policy, following the Fitzpatrick decision, stipulates the 'functional' assessment of capacity.

19 The functional approach has been applied in the Assisted Decision-Making (Capacity) Act 2015 and is also referred to in the Irish Mental Health Act 2001 Supreme Court judgment *In re a Ward of Court [1996] 2 IR 79*; and in the Irish High Court in *Fitzpatrick v K (No2) [2008] IEHC*.

20 An advance directive is defined in the Assisted Decision Making Capacity Bill 2015, as 'an advance expression made by the person of his or her will and preferences concerning treatment decisions that may arise in respect of him or her if he or she subsequently lacks capacity'.

21 An enduring power of attorney is a document drawn up by a person to the effect that he or she intends the power to be effective at any subsequent time when he or she lacks or shortly may lack capacity, empowering another to make certain decisions on their behalf. This is currently limited to property and personal care decisions, which does not include health or treatment decisions. However, there is provision in the Assisted Decision-Making (Capacity) Act, 2015 for the authority of enduring power of attorney be expanded to cover healthcare decisions.

22 A decision that would be consistent with what the patient would decide if they were competent. This decision would be based on information drawn from people who know the patient and understand their values e.g. carers, family members to whom the patient has expressed their views (McCarthy et al., 2010).

23 A decision made based on the well-being of the person according to their wishes and taking into account the harms and benefits of using different treatments compared with the harms and benefits in withholding treatments. Treatment is not started, or it is stopped if it is ineffective or futile and excessively burdensome or not clinically indicated (Mental Health Act 2001; *In re a Ward of Court [1996] 2 IR 79*; Irish Medical Council 2009).

3.2.3 Patient autonomy

In most European jurisdictions and the UN Declaration on Bioethics, it is ‘well established that a patient with capacity has an unequivocal right to refuse medical treatment’ and ‘this right of refusal is ethically defended by the principle of respect for patient self-determination or autonomy’ (McCarthy et al., 2011, p.274). Furthermore, it is generally accepted that ‘unless health professionals have concerns about a patient’s capacity or consent, they should respect these refusals even contrary to their expertise, their best judgement and their emotional response’ (McCarthy et al., 2011, p.275). This view is supported by a European Court decision, *Pichon and Sajous*²⁴, which states that the dominant right is that of the patient and not of the conscientious objector.

Individual autonomy is generally regarded as central to our understanding of advance planning, whereby everyone should have the right to articulate their preferences for end-of-life. This is the ethical basis of the IHF *Think Ahead* programme in Ireland and legislation in other countries (Wiesing et al., 2010).²⁵ The individual rather than the healthcare professional is regarded as the primary decision-maker. However, critics of advance care directives argue that they rely too much on the concept of patient autonomy, whereby the former competent self is perceived to have the authority to make decisions that will impact the well-being of their later, non-competent selves. Essentially, they argue that the individual may not have sufficient knowledge of their future illness to make an informed decision. Better, they say, that advance care planning should take place, ‘near the time when the person has some sense of what their illness entails, in conjunction with a doctor who is expert in the area, and which provides for reasonable flexibility in interpretation in terms of both complexity of the patterns of evolving illness and innovations in practice’ (O’Neill, 2014).

3.3 The policy context of Advance Care Planning in Ireland

In Ireland, it is possible to identify a number of policy statements supporting the concept of advance care planning.

3.3.1 The HSE

The practice of care planning is carried out within the health services, under a number of different forms, including strategic planning, palliative care and documentation. On the 6th May 2008 *the National Strategy for Service User Involvement in the Irish health service 2008-2013* was launched (Department of Health and Children and Executive, 2008). One of the seven strategic goals in this plan is ‘to develop the role of the ‘expert patient’, especially those with long-term illnesses, in developing their own care plan and in looking after their own condition’ (Drugnet Ireland, 2008, p.10). Two of the related actions to achieve this goal are: a) The promotion of patients as ‘partners with health professionals’ and b) The education of staff on the ‘importance of patient involvement in their care’ (Department of Health and Children and Executive, 2008, p.14). In ‘emphasising the idea of individual patient participation in care planning and self-care’ McCarthy (2011) observes that ‘the HSE strategic plan brings Ireland into line with international efforts to change the way illness is managed in the twenty-first century by health professionals and, increasingly, by patients themselves’ (McCarthy et al., 2011, p.167).

24 Eur.Ct.H.R. *Pichon and Sajous v France*, decision of 2nd October 2001 (Application 49853/99).

25 For example, the provisions of the German law on advance directives, which was introduced in September 2009, ‘combines more legal certainty with a liberal emphasis on patient autonomy and flexible, adaptable rights’ (Wiesing et al., 2010, p.779).

The HSE Palliative Care Programme

The *Palliative Care Programme* is one of the *National Clinical* programmes developed by the HSE's *Quality and Clinical Care Directorate*. A key workstream of the Palliative Care Programme is advance care planning, which will initially focus on older people with life-limiting illnesses. They plan to develop a universal documentation form for all settings. One of the programme's objectives for 2012 was the 'development of a national advance care planning programme which empowers patients and their families to express their wishes about treatment choices and care provision towards the end of life'. However, it is understood that this has yet to be developed. In terms of documentation, hospitals use health care records for every patient and these can perform a care planning function. Health care records include information related to health matters and relevant treatment plans.

The HSE National Consent Policy

The National Consent Advisory Group (NCAG) was convened in June 2011 under the auspices of the HSE's Quality & Patient Safety Directorate. The aim of the NCAG was to develop one overarching policy for consent in health and social care. The draft policy was approved in April 2013 and published as a formally approved document in May 2013, with a revision date of May 2016. The policy acknowledges that the overall survival rate after CPR is relatively low at 13-20%; the associated risks of long-term brain damage and disability, as well as traumatic side adverse effects including bone fractures and organ rupture. These considerations have prompted extensive national and international debate regarding the appropriate use of this procedure. Existing local and regional guidelines in Ireland relating to CPR and do not attempt resuscitation (DNAR) orders have shown a lack of consistency in how resuscitation decisions are made and documented and a lack of clarity about roles and responsibilities. The national policy aims to: 'provide a decision-making framework that will facilitate the advance discussion of service users' preferences regarding CPR and DNAR orders and to ensure that decisions relating to CPR and DNAR orders are made consistently, transparently and in line with best practice. It is also stated that this policy should be read in conjunction with the Medical Council's 2009 document, *Guide to Professional Conduct and Ethics for Registered Medical Practitioners*.

In the context of advance care planning, the policy states that the views of the individual are very important and that: 'In particular, service users are the best judges of their own quality of life'. The policy calls for healthcare professionals involved in the decision-making process to have the requisite experience, training, knowledge and communication skills to coordinate this process, stating that decision-making responsibility rests with the most senior member of the person's team. In the hospital setting this would be a consultant or registrar or the person's GP in other settings. The policy suggests that standardised DNAR forms should be developed in the future to ensure appropriate documentation of these decisions and facilitate them being communicated across settings.

Where a person might be considered to be approaching death, this policy states that:

'Cardiorespiratory arrest may represent the terminal event in their illness and the provision of CPR would not be clinically indicated. Attempting CPR when it is not clinically indicated may cause harm to the service user, increase his/her suffering and/or result in a traumatic and undignified death. In most cases, a sensitive but open discussion of end-of-life care will be possible in which service users should be helped to understand the severity of their condition...care provided should follow a palliative approach and focus on easing that service user's suffering and making him/her as comfortable as possible'.²⁶

26 National Consent Advisory Group, National Consent Policy, May-June 2012, Part 4 – Do Not Attempt Resuscitation (DNAR): 12

The policy sets out principles to be applied in reaching a decision about CPR. One of these is that if a person with capacity refuses CPR, or a person lacking capacity has a valid and applicable advance healthcare directive refusing CPR, this should be respected. Finally, the policy sets out principles in relation to consent and DNARs for HSE staff. It aims to provide a decision-making framework that will facilitate the advance discussion of personal preferences regarding CPR and DNAR orders and to ensure that decisions relating to CPR and DNAR orders are made consistently, transparently and in line with best practice (p. 95). The policy states that: 'It is recommended that service providers should develop specific mechanisms for the documentation and dissemination of decisions relating to resuscitation' (p.4).

3.3.2 Department of Health

The Department of Health's *Future Health: A Strategic Framework for Reform of the Health Service 2012 – 2015* commits to a focus on the rights and dignity of the person concerned, with care guided by the person's own views and wishes; a strengths-based approach to needs assessment, i.e. a focus on supporting and enhancing ability to enable active community living; and individual care plans with a focus on personal goals and outcomes.

3.3.3 Medical Council Ethical Guidelines

Para 41 of the Medical Council's Guide to Professional Conduct and Ethics 2009 states that 'Sometimes patients might want to plan for their medical treatment in the event that they become incapacitated in the future. This might include an advance refusal of medical treatment and/or a request for a specific procedure. However, you are not obliged to provide treatment that is not clinically indicated for a particular patient and that 'An advance treatment plan has the same ethical status as a decision by a patient at the actual time of an illness and should be respected on condition that: the decision was an informed choice, according to the principles of informed consent in paragraph 33; the decision covers the situation that has arisen, and the patient has not changed their mind.'²⁷

3.3.4 HIQA: National Standards for Residential Care Settings for Older People 2015²⁸

Since the publication of the *National Quality Standards for Residential Care Settings for Older People in Ireland in 2009*, these standards have been developed under eight themes relating to quality, safety, capacity and capability. These standards will replace HIQA Standard 16, which calls for nursing homes to engage with residents in relation to planning their end-of-life care and preferences.²⁹ Standard 1 is based on the theme of person-centred care and support and states that: the rights and diversity of each resident are respected and safeguarded; the privacy and dignity of each resident are respected; each resident's right to decline care and treatment is respected by the residential service.

27 Interestingly, the 2015 draft guide has the additional provision – 'An advance treatment plan has the same status as a decision by a patient at the actual time of an illness and should be followed and the guide set out the circumstances in which it should be followed. The Assisted Decision-Making (Capacity) 2015 provides: 'A specific refusal of treatment set out in an advance healthcare directive is as effective as if made contemporaneously by the directive-maker when he or she had capacity to make that direction'.

28 The new *Draft National Standards for Residential Care Settings for Older People* in Ireland were due to be published in April 2015 after a consultation process.

29 HIQA Standard 16: The resident's wishes and choices regarding end-of-life care are discussed and documented, and, in as far as possible, implemented and reviewed regularly with the resident. This includes his/her preferred religious, spiritual and cultural practices and the extent to which his/her family are involved in the decision making process. Where the resident can no longer make decisions on such matters, due to an absence of capacity, his/her representative is consulted.

The reasons for declining care and treatment should be discussed fully with the resident and documented in their care plan; each resident has a right to exercise choice and to have their needs and preferences taken into account in the planning, design and delivery of services; and each resident, where appropriate, is facilitated to make informed decisions, has access to an advocate and their consent is obtained in accordance with legislation and current evidence-based guidelines.

3.3.5 National Positive Ageing Strategy

While there is no specific mention of ACP or AHCD, one of the goals of the *National Positive Ageing Strategy* (2013) is to 'promote the development and delivery of a continuum of high quality care services and supports that are responsive to the changing needs and preferences of people as they age and at end of life'.

3.3.6 The Irish National Dementia Strategy (2014)

This strategy states that the independence of individuals should be protected for as long as possible and, as far as possible, according to their will and preferences. This will be one of the key features of the Assisted Decision-Making (Capacity) Act 2015, which will provide mechanisms to support and protect people with dementia who lack or will shortly lack capacity to make and communicate decisions.

3.4 The legal context of Advance Care Planning in Ireland

Advance healthcare directives are legally binding in Ireland, although up to the enactment of the *Assisted Decision-Making (Capacity) Act, 2015* there was no legislation governing advance care directives in Ireland.³⁰ This situation will change on the coming in to operation of Part 8 of the 2015 Act. The purpose of this Part of the Act is to: (a) Enable persons to be treated according to their will and preferences; and (b) Provide healthcare professionals with information about persons in relation to their treatment choices.

The enactment of the *Assisted Decision-Making (Capacity) Act 2015* will enable Ireland to ratify the *UN Convention of the Rights of Persons with Disabilities* (CRPD). In line with the principles of non-discrimination and equality before the law, as outlined in the CRPD, and in recognition of international recommendations regarding advance healthcare directive legislation [for example, under the Council of Europe's *Recommendation CM/Rec (2009) 11 on principles concerning continuing powers of attorney and advance directives for incapacity*], the legislative provisions for advance healthcare directives will facilitate individuals to make such directives pertaining to medical care and treatment and/or mental healthcare and treatment.³¹ The definition of treatment is specifically intended to encompass both physical health and also mental health, to ensure that a person can make decisions to refuse any such treatment (i.e. whether for therapeutic, preventative, diagnostic, palliative or another purpose) in his/her advance healthcare directive.

30 International law to which Ireland is bound is legally binding in Ireland. The *European Convention on Human Rights* has enshrined the right to self-determination. In December 2009, the *Council of Europe* issued a recommendation, which noted that where legal systems provide for advance care directives, increasing numbers of people avail of them. The statement recommended that Member States promote self-determination for adults in the event of their future incapacity. The 2006 *UN Convention on the Rights of Persons with Disabilities* also calls for states to facilitate people with disabilities to exercise their right to make choices and express preferences in relation to their care on a similar basis equal to those who do not have any disability.

31 Further legislation is necessary to enable AHDs for people who are involuntarily detained under the Mental Health Act 2001.

The Irish Law Reform Commission's Report, *Bioethics: Advance Care Directives* was published in September 2009. The report made 42 specific recommendations, including the following:

- It called for legislation to provide for advance care directives in the wider context of advance care planning, stressing that advance care directives are not limited to wishes made in a healthcare setting but rather encompass wider care settings as well.
- It suggested a draft Mental Capacity (Advance Care Directives) Bill 2009, intended to implement the recommendations.
- It called for a system for the registration of care preferences and advance care directives, citing the Irish Hospice Foundation as one possible organisation, which might support such a system.
- The Law Reform Commission's draft Bill on Advance Care Directives (2009) was set in the context of the Commission's proposed Mental Capacity Bill, which provided for a functional approach to the assessment of capacity, set out principles that must be followed for those who lack capacity, and provided an overarching modern framework for the protection of people who lack capacity. It is important that any decisions that are being made (to include health care decisions) for a person whose capacity is at issue are being made with the benefit of this overarching framework. In addition, an important aspect of the right of self-determination in the context of advance care directives is the right of a person to nominate a person to make decisions for them – a health care proxy.

The *Health Identifiers Act* was passed in 2014. The legislation provides the legal basis for individual health identifiers for health service users and health service providers. Identifiers are to be used across the health service, both public and private. HIQA is now in the process of developing standards for the government and management of identifiers. The *Assisted Decision-Making (Capacity) Act 2015* provides that the directive-maker gives notice of the making of an advance healthcare directive to the Director of the Decision Support Service. The 2015 Act also provides that the Director will be tasked with the requirement to establish and maintain a register of advance healthcare directives that have been notified to him or her. There may also be possible civil, criminal and statutory liabilities if a valid and applicable advance healthcare directive is not followed.

3.5 Advance Healthcare Directives in International Law

AHDs are underpinned by legislation in other jurisdictions (Table 3.1). However, even in countries where AHDs are legal and readily available, the number of people who have completed an advance healthcare directive remains consistently low in many countries, including Ireland, Germany and the US (see chapter four).

Table 3.1 Status of Advance Care Planning Internationally

| COUNTRY | LEGAL SITUATION |
|-------------------|--|
| US | The US has led the trend regarding policy development to enhance patient autonomy in this area (Ulrich, 2001). The Patient Self Determination Act was passed in 1990. Medical professionals in the US have a legal obligation to ask all patients in their care, regardless of age, if they have made an advance directive or appointed a power of attorney. Similarly, nursing homes in the US are required by statute to offer the facility to make an advance care directive to all people that are admitted. |
| England and Wales | Advance directives are legal in certain circumstances. The Mental Capacity Act 2005, allows people to make an advance directive or appoint a proxy to make decisions on their behalf. The British Government has upheld the right of every adult with mental capacity to consent to or refuse medical treatment. |
| Scotland | Advance care directives do not currently enjoy a statutory footing in Scotland but they would nevertheless be legally binding in Scotland under common law. Under the Adults with Incapacity (Scotland) Act 2000 any medical treatment administered to an adult with incapacity must take into account his or her 'past wishes and feelings', including advance directives. |
| Germany | In 2009, Germany passed a law on advanced directives based on the principle of the right to self-determination, applicable since 1 September 2009. Such law, based on the principle of the right of self-determination, provides for the assistance of a fiduciary and of the physician. |
| Netherlands | Netherlands passed the Medical Treatment Contracts Act (WGBO) in 1994, which provides for advance directives to be made by patients aged 16 or over. The Act calls for care providers to comply with patients' expressed preferences. The Termination of Life on Request and Assisted Suicide (Review Procedures) Act of 2002 contains provisions on advance directives relating to euthanasia. |
| New Zealand | Patients have a legal right to make advance directives in New Zealand under Right 7(5) of the Code of Health and Disability Services Consumers' Rights. The Health and Disability Commissioner (HDC) has produced an Advance Directive which allows people with mental illness to specify what treatment they agree to, and what treatment they do not consent to receive, if they become unwell in the future (Wareham, 2005). ³² |
| Canada | The Health Care Directives and Substitute Health Care Decision Makers Act was passed in 1997. In addition, 11 out of 13 states have federal legislation providing for advance care directives and/or proxies. Advance directives are recognised by the Canadian Medical Association and there is a National Framework for Advance Care Planning (2012). |
| Australia | Advance care directives are legally binding in Australia; however, there is significant variability in the terminology used and in the format and forms of advance care directives across territories and states, which makes it difficult for one jurisdiction to recognise an advance care directive from elsewhere. To remedy this, a National framework for Advance Directives was prepared in 2011 by a Working Group of the Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council. The framework sought to harmonise advance directives across jurisdictions in terms of terminology and formats used. Specialist Palliative Care and Advance Care Planning Advisory Services (Decision Assist) Project is a government-funded initiative to enhance the provision of palliative care and advance care planning services. The project is managed by a consortium of national health and aged care organisations, including Respecting Patient Choices (lead agency), Palliative Care Australia, CareSearch, the University of Queensland, Queensland University of Technology, the Australian and New Zealand Society of Palliative Medicine, Leading Age Services Australia (LASA), and Aged and Community Services Australia (ACSA). ³³ |

32 See also Advance Care Planning: A guide for the New Zealand health care workforce (Ministry of Health 2011)

34 <http://www.caresearch.com.au/caresearch/tabid/3104/Default.aspx>

3.6 Concluding comment

This review of the ethical, legal and policy dimensions of advance care planning highlights the widespread acceptance of the value of advance care planning, and the need to support it in legislation. International and national policy frameworks and legislation seek to protect rights of the individual by means of advance healthcare directives rather than leaving the decision-making to others in the event the person has diminished capacity. There are many examples where the courts have decided, both at national and European level, that the patient has the right to consent or refuse medical treatment on any grounds.

Policy frameworks have evolved from these experiences at a judicial level and from a realisation that societies are not homogeneous and the divergent views of different ethnic, religious, social class, and other divergent should be respected. In regard to advance care planning, the patient themselves have a right to be heard. As well as receiving training in ethical and clinical end of life decisions, doctors need to inform their clinical judgement and treatment by developing a trusting relationship with the patient and their family and ensure they kept fully up to date on the course of their disease and what might lie ahead.

CHAPTER FOUR: THE RATIONALE FOR ADVANCE CARE PLANNING³⁴

4.1 Introduction

This chapter will focus on the relative advantages and challenges of advance care planning and advance healthcare directives. The advantages of the broader notion of advance planning, as described in chapter one, are assumed to be self-evident. Thus, while we are not aware of any evidence that indicates people who plan ahead for financial, legal, or social issues are happier or live a better quality life than others who do not engage in such planning, there are many stories of the difficult and sometimes dire consequences that can result from a lack of planning e.g., family disputes over assets of a deceased person, funeral arrangements, organ donation, location of assets etc. It is also acknowledged that in spite of the self-evident benefits of advanced planning, people are generally reluctant to engage in advance planning for a variety of reasons, such as financial, cultural and expediency. Financial planning requires resources and a willingness to delay the use of personal resources. Furthermore, it is clear that many people cannot afford or are unwilling to invest in a private pension, especially since the recession began in 2008 (Moloney and Whelan, 2009). Equally, for a variety of cultural reasons, Irish people are not used to planning ahead in making wills or detailing their funeral preferences in case they 'tempt fate'. The remainder of this chapter will concern itself with advance healthcare planning.

4.2 Advantages of Advance Care Planning

The overwhelming weight of informed opinion and a growing body of empirical research suggest that ACP is a worthwhile process. It is a process that is increasingly recommended for patients approaching end-of-life, and more specifically, for patients with dementia or intellectual disability (Bekkema et al., 2014, Brooke and Kirk, 2014, Dempsey, 2013). Advance care planning (ACP) would appear to have few, if any, critics, with most legal and medical interests supporting it (Law Reform Commission, 2009, McCarthy et al., 2011). ACP is widely regarded as a 'feature of good clinical care in Ireland' and 'an important part of overall care' (Royal College of Physicians of Ireland, 2014, p.3). It is increasingly regarded as the 'the gold standard for patient-centred care' generally (McCarthy et al., 2011, p.275), and also for some high-risk groups, such as patients in high-risk surgical settings (Schuster et al., 2014). Furthermore, the ethical ethos and practice of advance care planning is increasingly embedded into Irish healthcare practice and policy. The enactment of specific legislation underpins this approach to healthcare. Some of the reasons why ACP is regarded positively are summarised below.

34 Unless otherwise stated, any reference to advance care planning in this chapter will also include advance healthcare directives.

First, research suggests that ACP can improve patient outcomes. In Australia, a randomised control trial by Karen Detering and her colleagues suggests that advance care planning improves end-of-life care, and that end of life wishes were much more likely to be known and followed in the patients who had been randomly assigned to receive advance care planning. Furthermore, they found that advance care planning reduces the incidence of anxiety, depression, and post-traumatic stress in surviving relatives (Detering et al., 2010).³⁵ The authors summarised the key findings from their research as follows:

‘End-of-life care is often poor and is not improved by focusing on completion of advance directives only. Coordinated, systematic patient-centred advance care planning improved end of life care and reduced the incidence of anxiety, depression, and post-traumatic stress in surviving relatives’ (Detering et al., 2010, p.847).

The findings from this study challenged the earlier landmark SUPPORT trial in the US, carried out in the mid 1990s, which found that documenting patient and family preferences for end of life care failed to improve care or patient outcomes (SUPPORT, 1995). Conversely, a literature review of 113 studies conducted by Dutch researchers, Brinkman-Stoppelenburg and her colleagues, found evidence that advance care planning positively impacts the quality of end-of-life care by increasing the use of hospice and palliative care (Brinkman-Stoppelenburg et al., 2014).³⁶

Second, ACP is increasingly perceived to be of benefit to patients with dementia. It is only recently that dementia has been recognised as ‘a terminal illness where end-of-life care needs to be discussed and planned with the patient and their family’ (Brooke and Kirk, 2014, p.490). However, it would appear that while ‘the whole ethos of ACP suggests great benefits’ for the patient, their families and professional caregivers (Dempsey, 2013, p.233), the evidence shows that ‘ACP is often not embedded in dementia services and that professionals and families or carers find discussions and decisions about the end of life both emotionally difficult and a source of considerable stress’ (Dempsey, 2014, p.269). Conversely, Poppe et al’s qualitative research in the UK reported that discussions with patients, carers and staff shortly after diagnosis of dementia found ACP ‘a positive intervention that helped them think about the future, enabled people with dementia to make their wishes known, and resulted in their feeling relieved and less worried about the future’ (Poppe et al., 2013, p.e60412).

Third, research suggests that some patients have considerable care needs, some of which could be met by the provision of advance care planning. A qualitative study carried out in the UK with 20 patients who were experiencing end-stage kidney disease found that patients reported considerable unmet and unaddressed needs, such as ‘fear, grief, denial, a shortage of information about their illness and progress, mixed experiences regarding involvement in decisions and a lack of opportunity to discuss their concerns, prognosis and future care’ (Bristowe et al., 2015, p.445). These are experiences that could be ameliorated by, amongst other things, good communication and ACP. The authors concluded that the results from their study highlight ‘the importance of ACP and information-sharing that is tailored to individual preferences and priorities’ (Bristowe et al., 2015, p.449).

35 They assessed 309 patients aged 80 years or older who were being treated in a large hospital in Melbourne. Among the 56 patients who had died by six months, they found that end-of-life wishes were much more likely to be known and followed in the patients who had been randomly assigned to take part in advance care planning.

36 Their findings are based on 113 studies, of which 45 studies reported on advance directives. This mixed base allowed them to study the impact of advance care planning with and without advance directives, and they concluded that complex advance care planning interventions may be more effective in meeting patients’ preferences than written documents alone.

Fourth, research suggests that advance care planning is broader than the traditional focus on preparing for incapacity, and that it can also help patients prepare for death. A Canadian study, based on interviews with 48 patients, reported that the participants felt that their purpose in ACP was 'to prepare for death and dying' and that their 'underlying goals included the exercise of control and an attempt to relieve burdens placed on loved ones'. In this study, advance care planning was viewed as a social process, rather than solely an exercise in personal autonomy or a means to cope with diminished capacity (Singer et al., 1998). Fifth, the review of ethics, policy and law in chapter three suggests that advance care planning adheres to international best practice by acknowledging the right of an individual to articulate his or her own preferences as they approach end-of-life.

Sixth, many people die without dignity in circumstances that are not what they would like (Walsh, 2013, Walsh and Harvey, 2011, McKeown, 2014). An increasing number of policymakers and healthcare professionals believe that 'failure to talk about and plan for death is one of the most significant obstacles to improving the quality of dying' (Swerissen and Duckett, 2004, p.11). Accordingly, planning ahead can help people to have a 'good death' which 'gives people dignity, choice and support to address their physical, personal, social and spiritual needs (Swerissen and Duckett, 2004, p.2). Some commentators suggest that a failure to plan adequately 'often leads to the lack of co-ordinated care' where, for example, GPs and hospitals can fail to liaise with each other (Parliamentary and Health Service Ombudsman, 2015, p.3). A reluctance or failure to engage in end-of-life planning may result in a patient receiving inappropriate or unwelcome treatment. Seventh, there are indications that advance care planning may be associated with healthcare savings for some people due to reduced demand for hospital care (Klingler et al., 2015, Dixon et al., 2015).

Challenges to Advance Care Planning

The overwhelming evidence on advance care planning suggests that ACP is a positive feature of healthcare and that, if it is undertaken systematically by trained staff, it will generate better quality end-of-life care. However, it is not always easy to implement due to a variety of factors, which are reviewed in chapter five.

4.3 Advance Healthcare Directives

While many of the points made concerning advance care planning above could also be made about the use of advance healthcare directives, AHDs have particular issues that are perceived to be distinctive, contentious and unresolved. It should be noted from the outset, however, that the number of empirical studies on advance healthcare directives remains quite low, although this is changing.

4.3.1 Advantages of Advance Healthcare Directives

First, research suggests that the use of advance directives can improve the quality of a patient's end-of-life (Ferrell et al., 2015) and increase family satisfaction (Livingston et al., 2013). In the US, a large-scale study of 3,746 individuals, over 60 years of age who had died between 2000 and 2006, found that patients who had prepared advance directives 'received care that was strongly associated with their preferences (Silveira et al., 2010). While, some of the findings from this ('Proxy') study have been criticised by a subsequent study, there is agreement that patients whose wishes are known 'do not receive medical care that is clearly antithetical to them' (Shapiro, 2012, p.230). A literature review

on advance care planning by Brinkman-Stoppelenburg et al, which included a substantial number of studies on written advance directives, found that advance care planning/advance healthcare directives often decreased life-sustaining treatment, and increased the use of hospice and palliative care and prevented hospitalisation (Brinkman-Stoppelenburg et al., 2014). Another literature review undertaken in the US on the impact of advance directives on the outcomes in patients with implantable cardioverter defibrillators (ICDs) found that advance directives ‘are becoming an essential part of care for the ICD population’ provided the patient’s preferences are discussed when they are healthy, and also afterwards in case the patient would like to make changes to their directive as their condition changes (Sellars et al., 2015, p.250)

Other studies have also found that the use of AHDs can improve the quality of patients’ lives when they are documented, particularly those with dementia (Sampson et al., 2010, Poppe et al., 2013, Wickson-Griffiths et al., 2014). A study of patients with dementia in London found that following an advance care planning intervention, there were ‘significant increases in documented advance care wishes arising from nursing home residents’ and relatives’ discussions with staff about end-of-life’ (Livingston et al., 2013, p.1849). Relatives reported increased satisfaction about decisions, and staff members were more confident about end-of-life planning and implementing advanced wishes. A UK study of 12 patients with dementia and eight carers found that the use of AHDs ‘enabled people with dementia to make their wishes known, and helped them to feel less worried about the future’ (Poppe et al., 2013,p.1). The importance of sharing the ACP/AHD documentation between health service providers was also highlighted in this study. A pilot study of the impact of advance care directives on health care outcomes in elderly patients found that total hospital days were reduced (Chen et al., 2015). The following observation by a nurse practitioner in the US, following a study of patients, highlights the perceived benefit of advance directives in primary care: ‘We feel that our patients truly are receiving the care that they want at the end of their lives. Advance directives hold the promise of the promotion of patient autonomy and the more human use of life-sustaining treatment’ (Duffield, 1998).

Second, policymakers and advocates in different countries are increasingly supporting the use of AHDs. The House of Commons Health Committee believe that people with dementia should have ‘equal access to end-of-life care as those dying as a result of other conditions’ and that ‘particular attention should be paid to discussing and documenting their wishes as early as possible following diagnosis’ (House of Commons Health Committee, 2015, p.17). Unfortunately, while the concept is often ‘well received’ healthcare staff can find the process difficult (Brooke and Kirk, 2014). Third, the provision of a legislative framework for the use of advance directives is widely regarded as a positive step, which brings Ireland in line with international legislation, update and replace the *Lunacy Regulations (Ireland) Act 1871*, respects the rights of the individual to take an active part in their life decisions.

4.3.2 Challenges to Advance Healthcare Directives

First, not all forms of advance care planning are regarded with approval and there is currently a ‘serious debate’ about the relative benefits of using advance healthcare directives in the implementation of advance care planning (Roth 2014, p.2). Thus, while most people may agree with the concept of advance care planning, there is considerable disagreement with the mandatory use of advance healthcare directives, particularly where they are legally binding. Some commentators believe that it is not realistic to assume a person will know how they will feel about end-of-life many years in advance, particularly if they have diminished capacity (O’Neill, 2014, Fagerlin and Schneider, 2004).

The introduction of AHDs into Irish legislation was a contentious issue. While some organisations, such as the Irish Law Reform Commission and the Irish Hospice Foundation, called for legislation to provide for advance healthcare directives to ensure that a person's wishes are carried out and that there is respect for individual beliefs and values (Law Reform Commission, 2009), others were more critical of this proposal. In its submission to the Department of Health on the draft general scheme for Advance Healthcare Directives, the Royal College of Physicians of Ireland expressed 'significant reservations' about advance care planning where they include legally-binding directives (Royal College of Physicians of Ireland, 2014, p.3). The Irish Medical Organisation also questioned the utility of advanced healthcare directives and cautioned that given the 'enormous complexity of individual decision-making as the end of life approaches', there is a 'real risk that legally-binding directives may serve as an obstacle rather than a support to good end-of-life planning' (Irish Medical Organisation, 2014, p.1). A number of consultants, including Professor Des O'Neill, believe that advance care planning can be 'counter-intuitive' if it occurs too far away from a person's end-of-life because the person may not have a sense of what their illness entails or knowledge of innovations in medical practice (O'Neill, 2014).

Second, the take-up of AHDs is quite low in many countries. A report by the Irish Council for Bioethics on Advance Healthcare Directives, for example, noted that 'despite substantial interest in and public support for the concept and importance of advance directives, the actual uptake of advance directives is quite low in most countries' (The Irish Council for Bioethics, 2007). Low usage rates have been reported for Germany (Evans et al., 2012), Ireland and the US. Approximately 10 percent of German adults had completed an AHD in 2007 (Lang and Wagner, 2007) and, allowing for the dated nature of the Irish research, 14% of Irish adults in 2004 (Weafer, 2004).³⁷ In the US a range of studies have recorded a low uptake of healthcare directives. One large-scale study of individuals aged 18 years and older reported that 26% of adult Americans have an advance directive (Rao et al., 2014).³⁸

The Pew Research Center's telephone survey of 1,500 adults in the US found that 29% of adults had an advance healthcare directive expressing their wishes for end-of-life care (Pew Research Center, 2006). Morrison's and Meier's study of 700 people 60 years and over living in New York city reported that more than one third of their participants had completed a health care proxy (Morrison and Meier, 2004). Pollack et al found that while more than 60% of individuals aged 18 years and older in Maryland wanted their end-of-life wishes to be respected, only about a third of them had completed advance directives (Pollack et al., 2010). Jones et al found that 28% of home health care patients in the US had an advance directive on record. Conversely, 65% of nursing home residents and 88% of discharged hospice care patients had an AD (Adrienne L. Jones et al., 2011). For some US commentators, a figure in the region of one third is very positive, especially since the corresponding figure in 1990 was 12% (Pew Research Center, 2006), others are more critical of what they perceive as lack of progress was 12%.

'Little progress has been made in increasing the utilization of ADs in the 20 years of their existence. Communication between patients, families and providers about end-of-life options and desired treatment remains infrequent and is often poor in quality. Remarkably low numbers of adults have completed directives or discussed their wishes with family members' (Waldrop and Meeker, 2012, p.368).

37 A statistically representative study of Irish adults commissioned by the IHF found that 14% of Irish people had written up an 'advance directive' or 'living will', while an additional 9% had 'seriously considered' doing so. Most (77%) had done neither of these.

38 This data was derived from 7946 adults aged 18 years and older who participated in the 2009 or 2010 Health Styles Survey.

4.4 Concluding Comment

The evidence presented in this chapter suggests that advance planning for end-of-life is generally regarded as worthwhile and beneficial for patients approaching end-of-life. It is also a requirement under the UN Convention and Council of Europe Recommendation, and now underpinned by Irish legislation. Most research suggests that ACP/AHD can improve the quality of care for the patient, their families, and healthcare professionals. Evidence to support the opposing view is not prevalent in the literature, although further research is required in this evolving area. One practical issue that has been shown to hinder the implementation of the advance planning process is the reluctance of healthcare professionals to initiate the end-of-life discussion in a timely manner. In Ireland it is expected that following the commencement of the legislation which includes a public awareness function for the Director of the Decision Support Service that we are likely to see the promotion of the making of advance healthcare directives. Other factors are also known to hinder the development of advance care planning/ advance healthcare directives. These barriers and barriers to advance planning are summarised in the following chapter.

CHAPTER FIVE: BARRIERS AND DRIVERS OF ADVANCE CARE PLANNING³⁹

5.1 Introduction

As previously mentioned in chapter four, the take-up of advance healthcare directives is surprisingly low in countries where it is legal and readily available. The aim of this chapter is to identify the main barriers to, and drivers of, advance care planning and advance healthcare directives.

5.2 Advance Care Planning

5.2.1 Drivers of Advance Care Planning

ACP is increasingly regarded as a ‘feature of good clinical care in Ireland’ and ‘an important part of overall care’ (Royal College of Physicians of Ireland, 2014, p.3). It is also linked to the notion of a good death where it would help to give people ‘dignity, choice and support to address their physical, personal, social and spiritual needs’ (Swerissen and Duckett, 2004, p.2). Planning ahead can provide better quality of care and avoid treatments that are not in the patient’s best interest (Lotz et al., 2015). It can also give people a sense of control by helping to clarify goals of care, which can prepare people for the dying process. Overall, the literature indicates that ACP positively impacts the quality of end-of-life care (Brinkman-Stoppelenburg et al., 2014). It is possible to identify a number of drivers to advance care planning, including the following;

Citizen-led initiatives

The IHF *Think Ahead* programme was developed following public consultation in 2009, and since then, thousands of Think Ahead forms have been requested and distributed to the public. Public health professionals and others have also shown their interest by their attendance at the bi-annual Forums, and IHF staff have given talks on this topic at the request of many different groups. The ‘*Let me Decide*’ is another initiative that advocates the use of advance healthcare directives in Canada and Ireland (Molloy, 2011; Cornally et al 2015).

Addressing unmet care needs

Advance care planning has been found to be helpful in addressing the needs of patients with dementia (Pope et al., 2013), and particularly those in long-term care homes (Wickson-Griffiths et al., 2014). It is also beneficial for other patients with advance, life-limiting illness, such as COPD (Gott et al., 2009) and end-stage kidney disease (Bristowe et al., 2015).

³⁹ Unless otherwise stated, any reference to advance care planning in this chapter will also include advance healthcare directives.

Staff training and interest

Research suggests that ACP interventions are most likely to happen where staff are trained to work in this area (Lund et al., 2015), and when professional caregivers are motivated to engage in the process (Van der Steen et al., 2014). If there is uncertainty about a prognosis, healthcare professionals can be reluctant to discuss end-of-life care with their patients (Sleeman, 2013). This is compounded when health professionals are uncertain of the value of ACP with dementia patients (Robinson et al., 2013). Some literature suggests that a key facilitator of ACP is to have a ‘dedicated professional’ available to educate both families and health professionals about ACP (Dening, 2011).

Underpinned by ethical, legal and policy framework

As outlined in chapter three, advance care planning respects patient autonomy and ensures patient’s wishes are known (McCarthy et al., 2011, Lotz et al., 2015). It is also consistent with international policy and legal trends in this area. It may be argued that having legal frameworks provides additional security and guidance to staff and healthcare providers to support the process if discussing advance plans.

Value for money

Preliminary research suggests that advance care planning would appear to be associated with healthcare savings for some people in some circumstances, such as people living with dementia in the community (Dixon et al., 2015). This is also the case with palliative care interventions, which has been found to be less costly than other forms of care (Smith et al., 2014).

5.2.2 Barriers to Advance Care Planning

It is possible to identify a number of barriers to advance care planning, including the following:

Death anxiety

Death is a taboo subject in many countries (Ipsos MORI, 2010, Van Doorslaer and Keegan, 2001) and many people are reluctant to engage in discussion or planning that is perceived to be personal. This reluctance to engage with death and dying is natural. As Kastenbaum states in *The Psychology of Death*: ‘It is not that easy to think about death. Often the mind recoils or skitters away. Even a highly disciplined mind may falter during its encounter (close or distant) with death’ (Kastenbaum and Aisenberg, 1976, p.ix). In a systematic literature review of the concept of death anxiety, Lehto and Stein found that death anxiety is both normal and universal, and is associated with heightened negative attitudes towards the elderly and ageing (Lehto and Stein, 2009).

Sheldon Solomon and colleagues have for decades examined the implications of facing up to our deaths on an individual and societal basis (Solomon, Greenber, and Pysz. 2015). They argue that keeping the ‘terror’ of thoughts of our own deaths at bay can result in desperate attempts to maintain certainty from other aspects of life – increased allegiance to strong religious beliefs, professional doctrines or cultural/political systems that have some illusion of permanence. Much of this process they argue is unconscious, but the unintended consequence is an increased lack of tolerance to others and outsiders who do not share the common cultural view, with ultimately negative repercussions.

These forces and individual conscious or unconscious death means some individuals are prevented from talking about death and planning their end-of-life care. A literature review by Ipsos MORI (Ipsos MORI, 2010) identified a number of factors why death is regarded as a taboo subject and why there is a reluctance to put plans in place for end of life and, in particular, end of life care, including:

- The trend for death to be ‘hidden away’ as it occurs predominantly away from the home and the community in a hospital or other institution.
- People often do not have a close experience with the process surrounding death until they are middle-aged because people are living longer. This leads to a feeling that death is a long way off and planning is not yet necessary.
- A lack of awareness or understanding of what end-of-life planning entails, and a lack of awareness of the plans that can be made in order to ensure their preferences are upheld in end of life care.
- GPs are often the first port of call for guidance on end of life care issues but some GPs often find it difficult to have these discussions with their patients, or indeed to discuss their own preferences.
- Healthcare professionals often report they are unsure of when to prompt discussions surrounding end of life care.
- Some ethnic minorities and cultures are highly uncomfortable discussing death.

Many people have an ambiguous relationship with dying and planning ahead for death. On the one hand, a majority of Irish adults believe it is important to discuss and record their preferences for end-of-life (Amárach Research, 2011), and many people are willing to record their end-of-life preferences if requested by a GP (O’Shea et al., 2014). Conversely, research also indicates that relatively few Irish people follow through on their ‘good intentions’. Only a minority of Irish adults have arrangements in place for what they would like to happen if they became terminally ill or died (Weafer, 2014c). Furthermore, very few people have appointed an enduring power of attorney, written an advance healthcare directive, or informed people where they would like to be cared for if nearing death (Weafer, 2014c). Similar trends have also been observed in the UK (Dying Matters Coalition, 2015).

Professional Uncertainty

Research suggests that advance care planning may not be implemented effectively because healthcare staff lack confidence and training in this area. As a result they often don’t know when to start ACP and they are uncertain concerning which types of interventions work best (Gott et al., 2009, Almack et al., 2012, Baughman et al., 2014). Some commentators have observed that some GPs tend to delay conversations about dying because they may feel that ‘discussing bad news will jeopardise their relationships with patients’ and that it will deprive patients of hope (Sleeman, 2013, p.197). This emotional dimension to the patient-professional relationship has also been noted by researchers and commentators (Lund et al., 2015, Murray, 2006). One study of medical oncologists in the UK found that around half of them preferred not to discuss resuscitation, advance directives or palliative care, until there were no more treatments (Keating NL et al., 2010) However, there is evidence to suggest that honest discussion may enable patients to feel more empowered (Davison and Simpson, 2006). In the words of GP and Professor, Scott Murray: ‘The main barrier (to advance care planning) is probably doctors’ reluctance to raise the issue of planning for death, because of the largely unfounded fear of destroying hope’. He goes to say that ‘Planning for death with our patients may be an uncomfortable concept but is likely to ender hope rather than dispel it’ (Murray, 2006, p. 868-9).

Patient lack of awareness and uncertainty

Many people do not engage in advance care planning process for a variety of reasons. In some instances, patients can be reluctant to participate in the advance care planning process because they are not 'ready or able to do so' (Barnes et al., 2007, p.23). Others are not given an adequate opportunity to engage in a discussion about their preferences and priorities (Bristowe et al., 2015). A number of commentators have highlighted that discussions regarding end-of-life care are not 'routine practice for people with dementia and their families' (Brooke and Kirk, 2014, p.490). A literature review by Australian researchers identified the following barriers to advance care planning in palliative care: having a non-malignant diagnoses, having dependent children, being African American, and uncertainty about advance care planning and its legal status (Lovell and Yates, 2014). Another literature review of the implementation of ACPs by UK researchers identified the following barriers: competing demands from other work, the emotional and interactional nature of patient-professional interactions around ACPs, problems in sharing decisions and preferences within and between healthcare organizations (Lund et al., 2015).

5.3 Advance Healthcare Directives

5.3.1 Enablers of Advance Healthcare Directives

Many of the same enablers noted for advance care planning are also applicable for advance healthcare directives. There is an increasing acceptance amongst health professionals and policymakers of the enhanced quality of end-of-life that results from the use of advance healthcare directives. This is particularly the case for patients with dementia but not exclusively. The use of advance healthcare directives is also facilitated by staff who are trained in this aspect of healthcare, and where patients and families understand the process involved. A solid legal and policy basis is also a key enabler. Conversely, it is clear that the uptake of advance healthcare directives is very low in many countries.

5.3.2 Barriers to advance healthcare directives

Some of the barriers preventing a higher uptake include the following;

Death anxiety

A lack of familiarity and understanding of end-of-life terminology may suggest that advance care planning and the use of advance healthcare directives is the same as euthanasia (Jeong et al., 2007). A study of 186 patients in France, over 75 years of age, found that advance healthcare directives could be potentially dangerous for patients as it might lead doctors to be less 'therapeutically aggressive' for patients with AHDs (Fournier et al., 2013).

Low awareness

A number of studies have found that people are reluctant to complete an advance healthcare directive because they are unfamiliar with the process. For example, ninety per cent of elderly French patients were unfamiliar with advance directives (Fournier et al., 2013).

Physicians and family members not convinced about the value of ACP for patients with dementia. An increasing number of commentators believe that advance care planning is a fundamental component of effective end-of-life care’ which should be offered to all consenting individuals’ particularly in the area of dementia where ‘subsequent loss of capacity can result in clear goals, and care which may become fragmented and not patient-centred’ (Dempsey, 2014, p.269). The importance of advance care planning for people with dementia or other conditions where their capacity is severely diminished has also been endorsed by empirical research (Poppe et al., 2013, p.1). Conversely, a range of barriers has been identified to the initiation of ACP discussions with people living with dementia (Table 5.1).

Table 5.1 Key barriers to ACP for people with dementia

| Barriers | Studies |
|--|---|
| 1. Lack of ACP knowledge in people with dementia, family members and health professionals. | (Dening, 2011) (Dickinson et al., 2013) (Poppe et al., 2013) |
| 2. Lack of understanding regarding the ‘right’ time to initiate ACP discussions. | (Dening, 2011) (Van der Steen et al., 2014) (de Vleminck et al., 2014) (Robinson et al., 2013) (Dickinson et al., 2013) |
| 3. Reluctance/avoidance of people with dementia and their family members to engage in ACP discussions. | (Dening, 2011) (Van der Steen et al., 2014) (de Vleminck et al., 2014) (Robinson et al., 2013) (Dickinson et al., 2013) |

Source: (Brooke and Kirk, 2014)

In their systematic review of literature, for example, Dening et al (2011) highlighted two common barriers: first, family members were unprepared to become involved in the decision-making process of end-of-life care if these discussion had not occurred with the person with dementia prior to their cognitive decline; second, health professionals lacked the knowledge and skills to ensure ACP discussions were initiated in a timely manner. In their review of literature, Brooke and Kirk (2014) believe that the literature reviews on this topic suggest ‘health professionals still lack the skills and knowledge to initiate ACP at an appropriate time prior to cognitive decline with patients with dementia and their family members’ (Brooke and Kirk, 2014, p.495).

It is also the case that some physicians are not convinced about the value of ACP, especially with children. A qualitative study with healthcare professionals who cared for severely ill children in Germany found that while paediatric advance care planning is perceived as helpful by providing an action plan for everyone and ensuring the patient/parent wishes are respected, nevertheless, the professionals experienced discomfort and uncertainty regarding end-of-life decisions and advance directives because physicians and non-medical care providers avoided taking responsibility for treatment limitations according to a minor's directive (Lotz et al., 2015). The introduction of ACPs into clinical practice can also be problematic because of the perceived additional workload and time involved with the process and associated documentation. It can be difficult for a GP to find the time to engage in ACPs in an increasingly time-pressurised clinical environment, where ACPs have to compete with other work in the clinical practice (Robinson et al., 2013, Lund et al., 2015).

5.4 Concluding Comment

This chapter has identified a number of enablers and barriers to advance care planning/advance healthcare directives. For the most part, they are similar for both forms of advance planning. Some drivers of advance care planning include: if people are made aware of the benefits of planning for end-of-life, if staff are sufficiently trained and engaged in the process, when it is underpinned by legislation, social policy and sound ethical principles, and where it can be shown to be cost-effective. Conversely, people are reluctant to engage in advance care planning because of death anxiety and an ambiguous relationship with death and dying, a lack of understanding of end-of-life issues, when healthcare professionals are unfamiliar with best practice, where GPs are reluctant to initiate the end-of-life conversation, and if cultural reasons make discussing death uncomfortable.

These findings suggest that tackling the barriers and supporting the enablers identified above could promote advance care planning/ advance healthcare directives. For example, a public education campaign about end-of-life issues, which sheds light on the advance care planning process and which highlights the benefits of the process, would help clarify what it entails and may reduce the public's death anxiety issues. Public campaigns are very expensive and it is very difficult to change behaviour and attitudes. It is likely that long-term funding would be required. The professional uncertainty is best addressed by means of training and other supports, such as the Guidelines currently being designed by the IHF.⁴⁰

40 *Final Journeys* is a course which aims to improve end-of-life care through raising awareness and empowering staff to become more competent, confident and comfortable when dealing with patients and families; and to enhance the communication skills of hospital staff so that they are better able to deal with people who are nearing end of life.

What Matters to Me is a course designed for staff working in community hospitals/ long-term settings. It is similar to the *Final Journeys* course, with some adaption to reflect the longer-term nature of staff-patient/resident relationships within community hospitals/long-term care settings.

Dealing with Bad News is a workshop, which aims to improve communication skills for healthcare staff that are dealing with or breaking bad news to patients and families.

CHAPTER SIX: THE IHF THINK AHEAD PROGRAMME⁴¹

6.1 Introduction

The Think Ahead programme is the flagship project of the National Council of the Forum on End of Life in Ireland, which is itself an initiative of the Irish Hospice Foundation.⁴² In 2009, the Forum on End-of-Life conducted a year-long nationwide public consultation to determine what issues mattered most to Irish people regarding death, dying and bereavement. Almost 200 submissions were received from a wide range of individuals and organisations. Town-hall meetings were organised around the country. 23 workshops were held and 108 presentations made as part of the consultation. One of the issues that emerged strongly from the submissions and feedback to the Forum was that the Irish public wanted some means of discussing and recording their preferences for end-of-life so that these could be followed should they ever be unable to communicate them. This led to the design of the IHF *Think Ahead* programme, a public awareness initiative that was launched by An Taoiseach, Enda Kenny in 2011 to guide and empower people in discussing and recording their care preferences in the event that they cannot speak for themselves due to emergency, serious illness or death. While it is aimed at the broader population, the initiative promotes positive ageing by empowering people to plan for the future, express their wishes and ensure those preferences are fulfilled. It also enables self-determination in the face of vulnerability and possible cognitive decline.

The Irish Hospice Foundation believes that at its most simple, advance planning for end-of-life is both a bottom-up and top-down process. Thus, while the Think Ahead programme is perceived to be an essentially citizen-led initiative that has been designed to empower people to ‘Think, Talk, Tell Record and Review’ their wishes for end of life, be they financial, legal, practical or directly associated with health and social care, the IHF also acknowledges that if these wishes are to be respected, a top-down approach is also required to ensure that the necessary legal, medical and educational frameworks are in place.

41 At the time of writing this paper, the IHF is engaged in the development of a number of resources to assist health care staff to deliver better healthcare, including advance care planning/ advance healthcare directives.

42 The Forum on End-of-Life in Ireland is an IHF initiative aimed at awareness raising, planning and promoting public debate on issues relating to death, dying and bereavement in Ireland. It was established in 2009, with a view to broadening the advocacy base of end-of-life beyond healthcare to include all agencies with a stake in promoting quality of life at the end-of-life in Ireland. The Forum was charged with linking with the public to identify what matters most to Irish people regarding end-of-life from a wide range of perspectives: social, health, economic, legislative, administrative, educational, cultural and religious. Among the aims of the Forum were: to promote a national conversation on dying, death and bereavement; to explore the views and concerns of the public and varying organisations; and to ensure that a wide range of views are heard

There are a number of elements to the Think Ahead Form:

1. A planning tool which allows a person to think about and plan for all aspects of their end-of-life by capturing people's health preferences, their views on life-sustaining treatment they would like used or withheld, their thoughts on CPR and organ donation, their legal and financial information, as well as their funeral and burial arrangements.
2. An advance healthcare directive within the Think Ahead form.
3. A public engagement initiative to raise awareness of the importance of thinking and planning ahead.
4. Related resources, information and discussions on the Think Ahead website (www.thinkahead.ie).
5. An advocacy programme aimed at ensuring that legislation is passed.

6.2 Aims and objectives of the Think Ahead programme

The aims of the 'Think Ahead' programme are:

1. To raise public awareness and interest in end-of-life and advance planning via the flagship project, Think Ahead.
2. To advocate for the speedy coming into operation of Part 8 of the *Assisted Decision-Making (Capacity) Act 2015* which provides the statutory framework for the making of advance healthcare directives and to support the HSE in the introduction of advance care planning.
3. To engage in a simplified process of developing a version of Think Ahead appropriate for people living with dementia.

The Think Ahead programme incorporates many different activities, such as lobbying, developing communication links, commissioning research and engaging with statutory bodies and voluntary organisations, to achieve the following objectives:

1. To develop a suite of multimedia information and public awareness tools for Think Ahead that build on the current information available, e.g. TV documentaries, information videos, advertisements, fact sheets, and webcasts.
2. To engage with the public unilaterally and through strategic alliances with existing organisations or influential 'champions' in a campaign over three years to encourage individuals, families and professionals to have conversations around end-of-life care.
3. To use appropriate national events to get the message of planning ahead to a wide audience in a positive and non-threatening manner.
4. To develop a strategic approach for the promotion of advance planning, on both a legislative basis and within health structures, via the HSE's national planning group for advance care directives and among health professionals working on the ground.
5. To encourage further research and wide dissemination of relevant national and international data by supporting research initiatives and encouraging strategic alliances.
6. To keep abreast of developments in terms of online repository options for Think Ahead forms or people's preferences in general.
7. To develop appropriate simplified tools to support people living with dementia.

6.3 Rationale of the Think Ahead programme

The *Think Ahead* programme has evolved for a variety of reasons, most of which have already been referred to earlier in this paper. First, much of the groundwork for the programme had already been put in place by various Irish and international bodies, such as the Law Reform Commission, HIQA and the UN (chapter three). Second, research commissioned by the IHF suggests that the majority of Irish adults would be interested in planning ahead for end-of-life. The majority of Irish adults believe there is not enough discussion on death and dying (Weafer, 2014c, Weafer, 2004), and that most Irish adults feel it is important to discuss and record preferences for end-of-life care and procedures for after their death (Amárach Research, 2011). Conversely, only a minority of people have told someone of their preferences or recorded their these preferences (Weafer, 2014a). This finding is consistent with international research, which indicates that while people view it as important and aspire to planning, there is a reluctance to put plans into place for end-of-life (Ipsos MORI, 2010, Dying Matters Coalition, 2015).

Third, a need was identified because a substantial number of people in Ireland and the UK are unfamiliar with end-of-life treatment and care terminology, such as advance care planning and advance directives (Dying Matters Coalition, 2015, McCarthy et al., 2010). Fourth, a growing body of evidence suggests that advance care planning can improve the quality of an individual's end-of-life and death (Detering et al., 2010, Singer et al., 1998). Fifth, a wide range of stakeholders indicated their support for the programme during the consultation process, including medical, legal, economic, educational, and organisations for older people.

6.4 The Think Ahead website and form

The key driver of the *Think Ahead* programme is the Think Ahead form, which acts both as an advance planning tool and a place to record an individual's preferences for end-of-life (Appendix A). The form highlights the broad remit of the Think Ahead programme, going beyond but also including healthcare. It comprises five sections: key personal information, care preferences, legal, financial, and when I die, which includes information on funeral options and organ and body donation choices. Since 2011, the Think Ahead form has undergone significant consultation with key stakeholders, including the Irish Medical Council, the Law Reform Commission, Citizens Information Board, HSE, NALA, Irish Pharmacy Union (IPU), Irish Association of Emergency Medicine (IAEM), National Ambulance Service, Pre-Hospital Emergency Care Council (PHECC), the Data Protection Commissioners, Irish College of General Practitioners, Money Advice and Budgeting Service, the Medical Protection Society (MPS), Irish Banking Federation, and the Clinical Indemnity Scheme. Think Ahead is partnered with 15 organisations, including Citizens Information and Active Retirement Ireland and is supported by the Law Reform Commission. At the time of writing, there are approximately 50,000 forms in circulation around the country. There is an increasing demand for Think Ahead briefings and training from health and social care professionals and from civil society organisations. In 2015 alone, 116 presentations were given to approximately 50 organisations, including medical and legal organisations.

Research suggests that the form can be highly effective in helping people to start conversations around death and dying. Research with members of the public found that 89% of people said that they would have discussions with family and friends about their wishes. Participants in two community-based pilots in Limerick and Louth in 2012 found that 80% of people felt Think Ahead would be of

interest to the general public and that it would encourage people to discuss end of life planning with loved ones. The majority of people found the form easy to use.

Research has also been carried out using Think Ahead in a variety of health care settings. An Irish study that involved 100 clinically stable patients in five GP training practices attending their GP for routine care found that most of these patients had no difficulty completing the form, three-quarters said they did not find completing the form upsetting, and the vast majority had discussions on end-of-life planning with family members as a result of reading the form (O’Shea et al., 2014). A recent study of 55 elderly patients that had been admitted to, and discharged from, an Irish Medicine for the Elderly inpatient service found that acceptability of the Think Ahead Form was high and many felt it should be more widely available (Barragry, 2015)⁴³. Research in nursing homes in Kildare found that there was an increase in care plans and recorded end of life decisions among residents (increase of 52.3% following the introduction of Think Ahead to staff and residents).

6.5 Concluding comment

The Think Ahead Form is one of the most comprehensive tools for end-of-life planning in the world. Over 40,000 Think Ahead forms have been requested and circulated to date and over 2,000 people have registered as online users of Think Ahead. The positive response from health professionals, civic society organisations and members of the public around Ireland suggests that Think Ahead is meeting a real need. There has also been considerable interest internationally. There are challenges however, to advance planning: the strong death denial in place means that people are still reluctant to discuss death. As such their wishes or concerns may not be sufficiently addressed, particularly if they are facing critical illness, dying, death or bereavement. Emotional and impulse factors can also play a role in preventing conversations. Thus, advance care planning in general and specific aids such as Think Ahead may benefit from public promotion campaigns, which are drawn from a theoretical knowledge of behavioural change.

Many health and social psychologists believe that a positive attitude or disposition alone is not enough to prompt behavioural change (e.g. Azjen et al)⁴⁴. They argue that people also need to believe that the desired outcome is likely to be achievable (e.g. that once recorded their wishes have a realistic chance of being fulfilled), is within their control (e.g., there is a feasible means of recording preferences), and that others, their family or peer group, consider it to be important. Therefore, more will need to be done to ensure that professionals and services are able to respond to the needs of patients – both by creating safe spaces for conversations on end of life to happen but also by developing policies to support advanced care planning and advanced healthcare directives.

43 Barragry, D. (2015) Results of an Acceptability Study on the Use of an Advance Care Planning Tool ('Think Ahead') in older Adults. Thesis submitted for the degree of M.Sc. by research at the university of Dublin, Department of Public Health and primary Care.

44 Models such as the theory of planned behaviour (Azjen et al) would suggest a concerted drive to promote the concept of planning for end of life which explicitly considers the family context for these decisions (normative influences), the means for making these decisions (access to tools and forms) and an informational/ policy input clarifying that recording preferences increases the likelihood of a more peaceful end of life and a better outcome for family. The theory of planned behaviour is not without its critics but other more contemporary models may be usefully applied to explain how people come to decide on converting idea to action (Sniehotta et al, 2014).

BIBLIOGRAPHY

- (HIQA), H. I. Q. A. 2008. National Quality Standards for Residential Care Settings for Older People in Ireland. Dublin: HIQA.
- ADRIENNE L. JONES, ABIGAIL J. MOSS & LAUREN D. HARRIS-KOJETIN 2011. Use of Advance Directives in Long-term Care Populations. USA: National Center for Health Statistics.
- ALMACK, K., COX, K., MOGHADDAM, N., POLLOCK, K. & SEYMOUR, J. 2012. After You: conversations between patients and healthcare professionals in planning for end of life care. *BMC Palliative Care*, 11.
- AMÁRACH RESEARCH 2011. Think Ahead Project. Dublin: Irish Hospice Foundation.
- BARNES, K., JONES, L., TOOKMAN, A. & KING, M. 2007. Acceptability of an advance care planning interview schedule: a focus group study. *Palliative Medicine*, 21, 23-28.
- BAUGHMAN, K. R., AULTMAN, J. M., LUDWICK, R. & O'NEILL, A. 2014. Narrative analysis of the ethics in providing advance care planning. *Nursing ethics*, 21, 53-63.
- BECK-GERNSHEIM, E. 2002. *Reinventing the Family. In Search of New Lifestyles*, Polity.
- BEKKEMA, N., VEER, A. J. E. D., HERTOOGH, C. M. P. M. & FRANCKE, A. L. 2014. Respecting autonomy in the end-of-life care of people with intellectual disabilities: a qualitative multiple-case study. *Journal of Intellectual Disability Research*, 58, 368-380.
- BHATNAGAR, S. & JOSHI, S. 2012. 'A Good Death' - Sequence (Not Stigma), to an Enigma Called Life: Case Report on End-of-Life Decision Making and Care. *American Journal of Hospice & Palliative Medicine*.
- BRINKMAN-STOPPELENBURG, A., RIETJENS, J. A. & HEIDE, A. V. D. 2014. The effects of advance care planning on end-of-life care: A systematic review. *Palliative Medicine*, 28, 1000-1025.
- BRISTOWE, K., HORSLEY, H. L., SHEPHERD, K., BROWN, H., CAREY, I., MATTHEWS, B., O'DONOGHUE, D., VINEN, K. & MURTAGH, F. E. 2015. Thinking ahead - the need for early Advance Care Planning for people on haemodialysis: A qualitative interview study. *Palliative Medicine*, 29, 443-450.
- BROOKE, J. & KIRK, M. 2014. Advance care planning for people living with dementia. *British Journal of Community Nursing*, 19, 490-495.
- CHEN, C., THORSTEINSDOTTIR, B., CHA, S., HANSON, G., PETERSON, S., RAHMAN, P., NAESSENS, J. & TAKAHASHI, P. 2015. Health care outcomes and advance care planning in older adults who receive home-based palliative care: a pilot cohort study. *Journal of Palliative Medicine*, 18, 38-44.
- DAVISON, S. & SIMPSON, C. 2006. Hope and advance care planning in patients with end stage renal disease: qualitative interview study. *BMJ*, 333.
- DE VLEMINCK, A., PARDON, L., BEERNAERT, K., DESCHEPPER, R., HOUTTEKIER, D., AUDENHOVE, C. V., DELIENS, L. & STICHELE, R. V. 2014. Barriers to Advance Care Planning in Cancer, Heart Failure and Dementia Patients: A Focus Group Study on General Practitioners' Views and Experiences. *Plus One*, 9.
- DEMOS 2013. A Time and a place. What people want at the end of life. London: Sue Ryder.
- DEMPSEY, D. 2013. Advance care planning for people with dementia: benefits and challenges. *International Journal of Palliative Nursing*, 19, 227-234.
- DEMPSEY, D. 2014. Advance care planning: taking time now will save time later. *NRC*, 16, 269-272.
- DENING, K. H. 2011. Advance care planning for people with dementia: a review. *International Psychogeriatrics*, 23, 1535-1551.
- DEPARTMENT OF HEALTH 2014. Helath in Ireland. Key Trends 2013. Dublin: Department of Health.
- DEPARTMENT OF HEALTH AND CHILDREN & EXECUTIVE, H. S. 2008. National strategy for service user involvement in the Irish health service 2008-2013.
- DETERING, K., HANCOCK, A., READE, M. & SILVESTER, W. 2010. The impact of advance care planning on end of life care in elderly patients: reandomised controlled trial. *BMJ: British Medical Journal*, 340.
- DICKINSON, D., BAMFORD, C., EXLEY, C., EMMETT, C., HUGHES, J. & ROBINSON, L. 2013. Planning for tomorrow whilst living for today: the views of people with dementia and their families on advance care planning. *International Psychogeriatrics*, 25.
- DIXON, J., MATOSEVIC, T. & KNAPP, M. 2015. The economic evidence for advance care planning: Systematic review of evidence. *Palliative Medicine*.
- DRUGNET IRELAND 2008. Service users to have greater voice in the health service. *Drugnet Ireland. Newsletter of the Alcohol and Drug Research Unit*.
- DUFFIELD, P. 1998. Advance Directives in Primary Care. *Nurse Practitioner Extra*, 98.
- DYING MATTERS COALITION 2015. Public Opinion on Death and Dying. London: National Council for Palliative Care and ComRes.
- ECONOMIST INTELLIGENCE UNIT 2015. The 2015 Quality of Death Index. Ranking palliative care across the world. London: The Economist.

- EVANS, N., BAUSEWEIN, C., MENACA, A., ANDREW, E., HIGGINSON, I., HARDING, R., POOL, R. & GYSELS, M. 2012. A critical review of advance directives in Germany: Attitudes, use and healthcare professionals' compliance. *Patient Education & Counselling*, 87, 277-288.
- FAGERLIN, A. & SCHNEIDER, C. E. 2004. Enough. The Failure of the Living Will. Hastings: Hastings Center Report
- FERRELL, B., SUN, V., HURRIA, A., CRISTEA, M., RAZ, D., KIM, J., RECKAMP, K., WILLIAMS, A., BORNEMAN, T., UMAN, G. & KOCZYWAS, M. 2015. Interdisciplinary Palliative Care for patients with Lung Cancer. *Journal Pain Symptom Management*.
- FOURNIER, V., BERTHIAU, D., KEMPF, E. & D'HAUSSY 2013. Are advance directives useful for doctors and what for?
- FRIENDS FIRST 2011. Pension Research 2011. Dublin: Friends First.
- GENERAL MEDICAL COUNCIL 2010. Treatment and care towards the end of life: good practice in decision-making. London: General Medical Council.
- GILLICK, M. R. 2004. Advance Care Planning. *New England Journal of Medicine* [Online]. Available: www.nejm.org [Accessed 2 April 2007].
- GOTT, M., GARDINER, C., SMALL, N., PAYNE, S., SEAMARK, D., BARNES, S. & HALPIN, D. 2009. Barriers to advance care planning in chronic obstructive pulmonary disease. *Palliative Medicine*, 23, 642-648.
- GRUNEIR, A., MOR, V., WEITZEN, S., TRUCHIL, R., TENO, J. & ROY, J. 2007. Where people die: A multilevel approach to understanding influences on site of death in America. *Medical Care Research & Review*, 64, 351-378.
- HAUGHTON, M. 2014. Flirting with the postmodern: moments of change in contemporary Irish theatre, performance and culture. *Irish Studies Review*, 22, 374-392.
- HOUSE OF COMMONS HEALTH COMMITTEE 2015. End of Life Care. fifth Report of Session 2014-15. London: House of Commons.
- INSTITUTE OF MEDICINE 2014. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. Washington DC: Institute of Medicine.
- IPSOS MORI 2010. Research to inform Social Marketing Interventions. Raising awareness in End of Life care - Secondary Research Report. London: Ipsos MORI.
- IRISH HOSPICE FOUNDATION 2010. Quality Standards for End-of-Life Care in Hospitals. Making end-of-life care central to hospital care. Dublin: Irish Hospice Foundation.
- IRISH HOSPICE FOUNDATION 2015. The End-of-Life Care Toolkit for staff working in residential care centres for older people. Dublin: Irish Hospice Foundation.
- IRISH HOSPICE FOUNDATION & NATIONAL COUNCIL OF THE FORUM ON END OF LIFE IN IRELAND 2013. Irish Hospice Foundation and National council of the forum on end of life in Ireland to push for advance care directives in new bill. In: LYNCH, C. (ed.). Dublin: Irish Hospice Foundation.
- IRISH MEDICAL ORGANISATION 2014. Submission to the Department of Health on the Draft General Scheme for Advance Healthcare Directives for Incorporation into the Assisted Decision-Making (Capacity) Bill 2013. Dublin: Irish Medical Organisation.
- JEONG, S. Y.-S., HIGGINS, I. & MCMILLAN, M. 2007. Advance care planning (ACP): The nurse as 'broker' in residential aged care facilities. *Contemporary Nurse*, 26, 184-195.
- KASTENBAUM, R. & AISENBERG, R. 1976. *The Psychology of Death*, London, Duckworth.
- KEATING NL, LANDRUM MB & ROGERS SO 2010. Physician factors associated with discussions about end-of-life care. *Cancer*, 116, 998-1006.
- KITZINGER, J. & KITZINGER, C. 2016. Increasing understanding and uptake of Advance Decisions in Wales. Wales: Public Policy Institute for Wales.
- KLINGLER, C., IN DER SCHMITTEN, J. & MARCKMANN, G. 2015. Does facilitated Advance Care Planning reduce the costs of care near the end of life? Systematic review and ethical considerations. *Palliative Medicine*.
- LANG, F. & WAGNER, G. 2007. Living will incidence in non-clinical population samples: conditions and reasons for refusal. *Dtsch Med Wochenschr*, 132, 2558-62.
- LAW REFORM COMMISSION 2009. Bioethics: Advance Care Directives. Dublin: Law Reform Commission.
- LEHTO, R. & STEIN, K. 2009. Death Anxiety: An Analysis of an evolving concept. *Research and Theory for Nursing Practice: an International Journal*, 23.
- LIVINGSTON, G., LEWIS-HOLMES, E., PITFIELD, C., MANELA, M., CHAN, D., CONSTANT, E., JACOBS, H., WILLS, G. & CARSON, N. 2013. Improving the end-of-life for people with dementia living in a care home: an intervention study. *International Psychogeriatrics*, 25, 1849-1858.
- LOTZ, J. D., JOX, R. J. & BORASIO, G. D. 2015. Pediatric advance care planning from the perspective of health care professionals" A qualitative interview study. *Palliative Medicine*, 29, 212-222.
- LOVELL, A. & YATES, P. 2014. Advance Care Planning in palliative care: A systematic literature review of the contextual factors influencing its uptake 2008-2012. *Palliative Medicine*, 28, 1026-1035.
- LUND, S., RICHARDSON, A. & MAY, C. 2015. Barriers to Advance Care Planning at the End of Life: An Explanatory Systematic Review of Implementation Studies. *PLoS One*, 10.

- MACCONVILLE, U. 2011. Opening Conversations. Developing a model for the Alzheimer Society of Ireland of best-practice palliative care interventions for people with dementia and their carers. Dublin: The Alzheimer Society of Ireland.
- MARIE LOUISE O'DONNELL 2015. Finite Lives. A study in how the State deals with issues relating to end of life. Dublin: Oireachtas.
- MCCARTHY, J., DONNELLY, M., DOOLEY, D., LOUISE, C. & DAVID, S. 2011. *End-of-Life Care. Ethics and the Law*, Cork, Cork University Press.
- MCCARTHY, J., WEAVER, J. & LOUGHREY, M. 2010. Irish views on death and dying: a national survey. *Journal of Medical Ethics*, 36, 454-8.
- MCKEOWN, K. 2014. Key Performance Indicators on Place of Care & Place of Death in the Health Service in Ireland. Dublin: Irish Hospice Foundation.
- MCCLOUGHLIN, K. & RHATIGAN, J. 2016. Join Bill United! Compassionate Communities in Limerick, Ireland. In: WEGGLEITNER, K. & KELLEHEAR, A. (eds.) *Compassionate Communities: Case Studies from Britain and Ireland*. London: Routledge.
- MCCLOUGHLIN, K., RHATIGAN, J., MCGILLOWAY, S., KELLEHEAR, A., LUCEY, M., TWOMEY, F., CONROY, M., HERRERA-MOLINA, E., KUMAR, S., FURLONG, M., CALLINAN, J., WATSON, M., CURROW, D. & BAILEY, C. 2015. INSPIRE (INvestigating Social and Practical supports at the End of life): Pilot randomised trial of a community social and practical support intervention for adults with life-limiting illness. *BMC Palliative Care*, 14.
- MOLONEY, M. & WHELAN, S. 2009. Pension Insecurity in Ireland. *Journal of the Statistical and Social Inquiry Society of Ireland*, XXXVIII, 75-100.
- MORHAIM, D. K. & POLLACK, K. M. 2013. End-of-Life Care Issues. A Personal, Economic, Public Policy, and Public Health Crisis. *American Journal of Public Health*, 103, e8-e10.
- MORRISON, R. S. & MEIER, D. E. 2004. High Rates of Advance Care Planning in New York City's Elderly Population. *Arch Intern Med*, 164, 2421-2426.
- MURPHY, D. 2000. Introduction. In: REDMOND, A. (ed.) *That was then, this is now*. Dublin: Stationery Office.
- MURRAY, S. A. 2006. Advance care planning in primary care. *BMJ*, 333.
- MYLEGACY. 2012. *How many people living in Ireland have a will?* [Online]. MyLegacy. [Accessed 14th May 2015].
- NATCEN 2013. British Social Attitudes: Attitudes Towards Dying. London: National Centre for Social Research.
- NAUGHTON, C., DRENNAN, J., TREACY, M. P., LAFFERTY, A., LYON, I., PHELAN, A., QUIN, S., O'LOUGHLIN, A. & L. DELANEY 2010. Abuse and Neglect of Older People in Ireland. Dublin: National Centre for the Protection of Older People, UCD School of Nursing, Midwifery and Health Systems.
- O'MAHONY-BROWNE RESEARCH CONSULTANTS 2005. Dying and Death in an Acute Hospital: Exploring the Views and Experiences of Hospital Staff. *Hospice friendly Hospitals Programme*. Dublin: Irish Hospice Foundation.
- O'NEILL, D. 2014. Care plans need to be as individual as the person. *Irish Times Health Plus*, p.16.
- O'SHEA, B., MARTIN, D., BRENNAN, B., BAILEY, O., MCELWEE, O., O'LEARY, F. & DARKER, C. 2014. Are we ready to 'Think Ahead'? Acceptability study using an innovative end of life planning tool. *Irish Medical Journal*, 107.
- PARLIAMENTARY AND HEALTH SERVICE OMBUDSMAN 2015. Dying without dignity. Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care. London: Parliamentary and Health Service Ombudsman.
- PATRICIA RICKARD CLARKE 2013. Submission to the Committee on Health and Children Public Hearings on End of Life Care, 24th October 2013. Dublin: National Council of the Forum on End of Life in Ireland.
- PEW RESEARCH CENTER 2006. Strong Public Support for Right to Die: More Americans Discussing and Planning End-of-Life Treatment. Washington DC: Pew Research Center for the People & the Press.
- POLLACK, K., MORHAIM, D. & WILLIAMS, M. 2010. The public's perspectives on advance directives in Maryland: implications for state legislative and regulatory policy. *Health Policy*, 96, 57-63.
- POPPE, M., BURLEIGH, S. & BANERJEE, S. 2013. Qualitative Evaluation of Advanced Care Planning in Early Dementia (ACP-ED). *Plus One*, 8.
- RANDAL 2009. The Mental Capacity Act: Implications for Palliative Care. *EAPC, 11th Congress*. Vienna, Austria.
- RAO, J. K., ANDERSON, L. A., LIN, F.-C. & LAUX, J. P. 2014. Completion of Advance Directives Among U.S. Consumers. *American Journal Prev Medicine*, 46, 65-70.
- ROBINSON, L., DICKINSON, C., BAMFORD, C., CLARK, A., HUGHES, J. & EXLEY, C. 2013. A qualitative study: Professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but ...'. *Palliative Medicine*, 27, 401-408.
- ROTH, L. 2014. Advance Care Directives. NSW: NSW Parliamentary Research Service.

- ROYAL COLLEGE OF PHYSICIANS OF IRELAND 2014. Towards a Humane, Practical and Evidence-Based Approach to Advance Care Planning. Public Consultation on Advance Healthcare Directives. Dublin: Royal College of Physicians of Ireland.
- SAMPSON, E. L., JONES, L., THUNÉ-BOYLE, I. C., KUKKASTENVEHMAS, R., KING, M., LEURENT, B., TOOKMAN, A. & BLANCHARD, M. R. 2010. Palliative assessment and advance care planning in severe dementia: An exploratory randomised controlled trial of a complex intervention. *Palliative Medicine*, 25, 197-209.
- SCHUSTER, A. L., ASLAKSON, R. A. & BRIDGES, J. F. 2014. Creating an advance-care planning decision aid for high-risk surgery: a qualitative study. *BMC Palliative Care*, 13.
- SELLARS, M., DETERING, K. M. & SILVESTER, W. 2015. Current advance care planning practice in the Australian community: an online survey of home package case managers and service managers. *BMS Palliative Care*.
- SHAPIRO, S. P. 2012. Advance Directives: The Elusive Goal of Having the Last Word. *NAELA Journal (National Academy of Elder Law Attorneys)*, VIII, 205232.
- SILVEIRA, M., SCOTT, K. & LANGA, K. 2010. Advance directives and outcomes of surrogate decision making before death. *The New England Journal of Medicine*, 362.
- SINGER, P. A., DOUGLAS K, M., LAVERY, J. V., THIEL, E. C., KELNER, M. & MENDELSSOHN, D. C. 1998. Reconceptualizing Advance Care Planning From the Patient's Perspective. *Archives of Internal Medicine*, 158, 879-884.
- SLEEMAN, K. 2013. End-of-Life communication: let's talk about death. *J R Coll Physicians Edinb*, 43, 197-9.
- SMITH, S., BRICK, A., O'HARA, S. & NORMAND, C. 2014. Evidence on the cost and cost-effectiveness of palliative care: A literature review. *Palliative Medicine*, 28, 130-150.
- SOLOMON, S., GREENBERG, J. & PYSZCZYNSKI, T. 2015. *The worm at the core: on the role of death in life*, London, Allen Lane.
- SUPPORT 1995. A controlled trial to improve care for seriously ill hospitalised patients. The study to understand prognoses and preferences for outcomes and risk of of treatments. *JAMA (The Journal of the American Medical Association)*, 274, 1591-8.
- SWERISSEN, H. & DUCKETT, S. 2004. *Dying Well*. Australia: Grattan Institute.
- THE IRISH COUNCIL FOR BIOETHICS 2007. Is it time for advance care directives? Dublin: The Irish Council for Bioethics.
- ULRICH, L. 2001. *The Patient Self-Determination Act: Meeting the Challenges in Patient Care*, Washington DC, Georgetown University Press.
- VAIL, K., JUHL, J., ARNDT, J. & AND VESS, M. 2012. When death is good for life: Considering the Positive Trajectories of Terror Management. *Personality and Social Psychology Review*, 16, 303-329.
- VAN DER STEEN, J., SOEST-POORTVLIET, M. C. V., HALLIE-HEIERMAN, M., ONWUTEAKA-PHILIPSEN, B. D., DELIENS, L., BOER, M. E. D., BLOCK, L. V. D., UDEN, N. V., HERTOOGH, C. M. & VET, H. C. D. 2014. Factors associated with initiation of advance care planning in dementia: a systematic review. *Journal of Alzheimer's Disease*, 40, 743-757.
- VAN DOORSLAER, O. & KEEGAN, O. 2001. *Contemporary Irish Attitudes towards Death, Dying and Bereavement*, Dublin, Royal College of Surgeons.
- WALDROP, D. P. & MEEKER, M. A. 2012. Communication and advanced care planning in palliative and end-of-life care. *Nursing Outlook*, 60, 365-369.
- WALSH, K. 2013. Homelessness, Ageing and Dying. Exploratory research looking at the needs of older people who are homeless as they age, and are faced with the issues of serious ill-helath and dying. *Age & Opportunity. Life is for Living*. Dublin: Simon Community.
- WALSH, K. & HARVEY, B. 2011. Older People - Experiences and Issues. *Report of the Commission of Older People*. Dublin: St. Vincent de Paul.
- WAREHAM, P. E. A. 2005. Advance Directives: the New Zealand context. *Nursing Ethics*, 12, 349-359.
- WEAFER, J. 2004. Nationwide Study of Public Attitudes and Experiences Regarding Death and Dying 2004. Dublin: The Irish Hospice Foundation.
- WEAFER, J. 2014a. The Palliative Care Needs of People with Advancing Neurological Disease in Ireland. Dublin: The Irish Hospice Foundation/ The Neurological Association of Ireland.
- WEAFER, J. 2014b. *Thirty-Three Good Men: Celibacy, Obedience and Identity. A Sociological Study of the Lived Experience of Irish Diocesan Priests in Modern Ireland, 1960-2010*, Dublin, Columba.
- WEAFER, J. A. 2014c. Irish Attitudes and Experiences Towards Death and Dying: A Comparative Study, 2004-2014. Dublin: The Irish Hospice Foundation.
- WHICH? 2015. Dying better. The consumer experience at the end of life. *Consumer insight 2015*. London: Which?
- WICKSON-GRIFFITHS, A., KAASALAINEN, S., PLOEG, J. & MCAINEY, C. 2014. A review of advance care planning programs in long-term care homes: Are they dementia friendly? *Nursing Research and practice*, 2014.
- WIESING, U., JOX, R. & HSSLER, H.-J. 2010. A new law on advance directives in Germany. *Journal of Medical Ethics*, 36, 779-783.

APPENDIX 1: THE THINK AHEAD FORM



The Think Ahead form can be downloaded at
<http://www.thinkahead.ie/think-ahead-form-2/>



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at end of life for all

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