

Submission to the Committee on Health and Children Public Hearings on End of Life Care

24 October 2013

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Forum on End of Life in Ireland.**

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Introduction

The National Council of the Forum on End in Ireland welcomes the initiative of the Joint Oireachtas Committee on Health and Children to hold hearings into how people are being cared for in Ireland at the end of their lives and how that care can be improved.

We congratulate all of the Deputies and Senators on the committee, led by Chairman Jerry Buttimer, who have decided to consider what is perhaps the last taboo in Irish society.

With up to 29,000 people dying in Ireland every year and as many as 290,000 people newly bereaved annually, it is appropriate that our national parliament should consider the many issues that patients, their loved ones and professionals face in ensuring that people have a dignified final journey.

This submission gives a brief overview of the work of the National Council of the Forum on End of Life in Ireland and will focus on a number of areas which we believe will help citizens to secure a positive end-of-life experience in line with their preferences and for their families to start their bereavement journey with a positive first step.

The reforms proposed involve:

1. Promote openness to change policy and practice
2. End-of-life proofing our buildings
3. Regulation of the funeral services industry
4. The need for a national end of life and bereavement strategy.
5. Advance care planning

Most of this submission will be concerned with the importance of actively promoting advance care planning which is the single biggest measure that the National Council of the Forum on End of Life in Ireland promotes in order to secure a good death for Irish citizens.

The work programme undertaken by the National Council and particularly our work in promoting advance planning is rooted in the public consultation process that we engaged in over the course of a year from 2009.

A. National Council of the Forum on End of Life in Ireland

The National Council of the Forum on End of Life in Ireland - Chaired by former Supreme Court Judge, Mrs Justice Catherine McGuinness - was formed in July 2010 following an extensive year-long public consultation (2009-2010) by the Forum (outlined below which identified what end-of-life issues mattered most to people.

The National Council was established with a view to broadening the advocacy base of end of life beyond health care. It considers all issues relating to end of life, including legal, economic, administrative and social aspects.

The National Council of the Forum on End of Life in Ireland is an initiative of the Irish Hospice Foundation (IHF) and meets at least four times a year. Membership of the National Council reflects a wide range of stakeholders and the diversity of end of life issues in Irish society.

Forum on End of Life in Ireland public consultation 2009-2010

The Forum conducted a year-long public consultation which asked the Irish public about the issues that mattered most to them around dying, death and bereavement.

The Forum received 167 written submissions from organisations and members of the public. It ran 23 workshops at which 108 presentations were given. People also attended nine public meetings nationwide.

Following its examination of submissions and presentations made to the Forum, the Forum has focused on a number of areas:

A baseline report of the proceedings which outlines the main themes, messages and issues raised by contributors to the Forum, *Perspectives on End of Life in Ireland: Report of the Forum on End of Life*, was published in 2009. It formed the basis for an initial Action Plan¹ based around 10 key action areas.

1. Availability and Access to services
2. Carers
3. Information and Communication
4. Spiritual and Psychological Support
5. Financial, Legal and Administrative Issues

¹ Available on the Irish Hospice Foundation website, www.hospicefoundation.ie

6. Ethical Engagement
7. Physical Environment
8. Standards and Regulation
9. Planning and Co-ordination
10. Public Engagement

National Council membership:

- Mrs. Justice Catherine McGuinness, Chairperson
- Catriona Crowe, Head of Special Projects, National Archives of Ireland
- Dr. Brian Farrell, Dublin City Coroner, Barrister-at-Law
- Dr. Ciaran Browne, Head of Acute and Palliative Care Services, Health Service Executive
- Dr. Ita Harnett, Consultant in Palliative Medicine, Galway
- Dr. Geoff King, Director, Pre-Hospital Emergency Care Council
- Dr. Deirdre Madden, Senior Lecturer, UCC Law Department
- Ita Mangan, Barrister/Murphy Commission Member
- Úna Marren, Convenor of the Network of Hospice Friendly Hospitals
- Sharon Foley, CEO, Irish Hospice Foundation
- Mr. Gus Nichols, Irish Association of Funeral Directors
- Seán Ó Laoire, Past President, Royal Institute of the Architects of Ireland
- Professor David Smith, Associate Professor Health Care Ethics, RCSI
- Dr. Max Watson, Consultant in Palliative Medicine at Northern Ireland Hospice
- Patricia Rickard Clarke, former Law Commissioner and solicitor
- Mervyn Taylor, consultant with expertise in end of life issues
- Senan Turnbull, retired senior civil servant and Chair of the Think Ahead Project Team

Principles underlying the work of the Forum

Based on the Forum's findings there are a number of inclusive principles which must underpin the Action Plan:

- **Death is a part of the life-cycle:** In this country we have adopted a life-cycle approach in national policy and planning. Death is a significant part of the life-cycle. End of life, death and bereavement must be integrated in planning initiatives for all age groups. There should be a provision to monitor the development and implementation of national social policy in Ireland on dying, death, and bereavement.
- **End of Life is everybody's business:** Contributions to the Forum identified a wide range of financial, legal, environmental, administrative, cultural and educational measures, which might be taken to improve the quality of life of those at end of life and of bereaved persons.

Separate action plans should be drafted for the attention of particular groups of people working in different sectors.

- **End of Life is a public health matter:** The responsibility for articulating and responding to end of life questions, including questions about end-of-life care, should not be left only to those who provide hospice and palliative care services. We must see and treat dying, death and loss as public health matters; they must be anticipated, and any harm that they cause the individual must be minimised by building our capacity to show solidarity with the dying and the bereaved. Community development, education, legislation and policy changes should be adopted using a public health approach to end-of-life.
- **High quality palliative care should be available to all:** High quality, person-centred palliative care should be available to all, regardless of age or circumstances, including psychological and spiritual care. Families and carers should also be supported.
- **Everyone is entitled to die with dignity:** The National Council is committed to ensuring that conditions of privacy and respect prevail in end-of-life care, including improving availability of private rooms for those that want them.

Activities of the Forum 2013-2015

Changing policy and practice - Recommendation to extend authority to pronounce death to nurses and paramedics

It is essential that our health services and the professionals who deliver care are open to both review and change practices which are no longer effective or hamper the delivery of the best possible care.

The Forum produced a position paper in 2012 recommending that authority to pronounce death be extended to nurses and paramedics.

This was raised as an important issue during the year-long public consultation that was conducted by the Forum in 2009-2010. Submissions from medical professionals and from bereaved families spoke of the inefficiencies inherent in processes of pronouncement as they currently stand.

The fact that doctors have sole responsibility in the pronouncement of deaths, while nurses or ambulance staff are amply qualified, means that doctors are frequently called away from more senior medical duties, causing delays and impacting on the quality of care provided.

Extending this responsibility to other healthcare personnel would address this problem and would make for faster and more efficient services.

Similarly, reducing the time it takes to register and certify death will enhance service provision to grieving families.

The Forum prepared a discussion paper outlining this proposal which outlines the rationale for extending authority to senior nurses and advanced paramedics. This document summarises the legal context and outlines the scenarios in which death would be pronounced by senior nurses and advanced paramedics.

It is important to note that Irish law does not preclude against extending authority to pronounce death. The basis for doctors pronouncing death is found in common law rather than statute and legislation would not be required to extend this responsibility.

While the law does not require a doctor to confirm that a death has occurred; to view the body of a deceased person; or to report the fact that a death has occurred, it does require the doctor who attended the deceased during the last illness to issue a certificate detailing the cause of death. For this reason we are limiting our proposal to pronouncement and not certification of death.

This paper is currently being reviewed by the HSE with a view to drafting a policy to extend this authority to nurses. The recommendation has also been approved by the Medical Committee of the Pre-Hospital Emergency Care Council, the regulatory body for paramedics in Ireland, who are progressing it.

Physical environment

Dignity is about respect for the individual and the quality of the physical environment has the power to enhance or detract from the dignity of patients, families and staff.² The physical environment is a prime example of the an end of life issue that goes beyond the domain of health and one that would need to be addressed as part of an End of Life Strategy.

Research has shown that better and more appropriate design can promote good care and organisational culture and can enhance the experience of people at end of life. Good design can also play a significant role in lower costs of care. Privacy is of paramount importance for individuals and their loved ones at end of life. Research shows that single occupancy rooms reduce costs of care by reducing the risk of infection, reducing medication errors, lowering length of stay and the number of falls (Ulrich, 2003).

In 2007, a report on the quality of the physical environment of hospitals in Ireland was commissioned by the IHF.³

The results included:

- The lack of facilities for private consultations and conversations in situations where confidentiality is critical
- The under-provision of single room accommodation
- The extent to which already very limited single-room accommodation is denied to the dying and their families because of the emerging priority given to infection control and isolation
- The lack of facilities for families
- The inadequate working conditions of staff
- The numbers of patients sharing a ward/ward section and the lack of adjacent sanitary Facilities
- The poor condition of mortuaries and associated family rooms
- The use of clinical and family areas for administrative and office use
- The lack of provision for different religious traditions and beliefs
- The lack of attention to external and natural surroundings

The IHF's Hospice Friendly Hospital Programme's Design and Dignity Guidelines were developed in 2008 to address these concerns. The Design and Dignity projects fund "exemplar" projects in public hospitals to transform the way hospital spaces are designed for people at the end of life and their families. The 11 hospital projects are located in Dublin, Sligo, Cork, Limerick, Meath, Tipperary, Mayo and Kilkenny. The project is co-funded by the IHF and the HSE.

The Forum is committed to building on this work. The Forum hosted a workshop in September 2012 with key stakeholders. The Forum is currently developing a work plan to address end of life issues relating to the physical environment. This may include advocating for local authorities to ensure that

² Hospice Friendly Hospitals, Design and Dignity Guidelines, June 2008

³ Design and Dignity Baseline Review, Tribal UK, 2007

their local development plans are “end-of-life proofed” to facilitate people to be cared for and to die in their own homes.

Regulation of the funeral services industry

The Forum believes that the funeral services industry should be regulated and supports the development of best practice guidelines for funeral service providers.

There are currently no barriers to entry and no licensing in an industry responsible for the burial or cremation of the 30,000 people who die in Ireland every year. There are no regulations or standards in the area of embalming which is often carried out by untrained personnel in inadequate hospital premises. Cremation, which is becoming an increasingly popular option, is not governed by any law.

The Forum is currently working with the Irish Association of Funeral Directors to develop best practice guidelines for funeral service providers in Ireland.

Advance care planning

Over the past two years the Forum has been advocating for the introduction of legislative provision for advance directives. There has been a commitment by Government that this will be added to the Assisted Decision Making (Capacity) Bill at committee stage.

Think Ahead is the flagship project of the Forum and was launched by An Taoiseach Enda Kenny in 2011. Think Ahead guides members of the public in expressing their preferences around end of life and seeks to initiate dialogue about these issues.

While the Think Ahead form includes health care preferences, it also encompasses legal and financial affairs, as well as funeral preferences and wishes regarding organ donation and post-mortems.

There have been several studies on Think Ahead conducted with health professionals and their patients and also with members of the public which have had very positive results.

Dr Brendan O’Shea, GP and Associate Professor on the TCD GP Training Scheme, has coordinated two pilots involving 100 patients and several GP practices in Dublin. The findings from these have been written up and accepted by the Irish Medical Journal. They are due to be published soon.

Dr Brendan O’Shea is working on another study with KDoc in Kildare from August 2013-March 2014 to look at the introduction of Think Ahead with patients across health care settings, including GP practices, Naas Hospital, nursing homes, palliative care teams and emergency services.

Think Ahead aims to bring about a culture change in Ireland to encourage people to THINK, TALK, TELL: **think** about their preferences around end of life, **talk** about their wishes with professionals and **tell** their loved ones about their decisions and ensure they understand these wishes. A national public campaign is currently being planned.

Public meetings

The Forum holds public meetings on issues of public interest relating to end of life. Two of these meetings were held in June 2012 on organ donation and Do Not Attempt Resuscitation Orders.

The Forum has developed a work plan for 2013-2015 which is appended to this submission.

B. Advance care planning

1. Ethical rationale for advance care planning

1.1 Context

Advances in medical technology present challenges to patients' understanding, choices and well-being. Very ill people at end of life 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 bring new ethical dilemmas. The moral weight that is **given to patient autonomy derives from:**

- Past abuse in medical research and medical paternalism
- Recognition of the rational reflective nature of human beings who choose values and want to live by them (McCarthy, 2012)
- Emerging evidence that advance care planning improves the quality of patient care

1.2 Advance care planning: origins, definitions and rationale

Advance care planning is the process of care planning that generally occurs in an end of life context. The Quality Standards for End of Life Care in Hospitals that was developed by the Hospice Friendly Hospitals programme of the IHF defines advance care planning as the process of discussion between a person and their carer, and often those close to them, about future care. Advanced care planning usually takes place in the context of an anticipated deterioration in the person's condition in the future, with increasing loss of capacity to make decisions and/or ability to communicate their wishes. However, this is not necessarily always the case. Issues which may be discussed are the service user's concerns, his/her values or personal goals for care, his/her understanding of their illness or prognosis, in addition to particular preferences for types of care or treatment and preferred place of care in the future.⁴

Current thinking advocates a holistic approach that recognises the values of the process and outcomes of care planning in general across the health sector, a process that constitutes advance care planning when carried out in the context of end of life care. Advance care planning also serves to assist health care professionals to provide appropriate care and facilitate decisions that take into

⁴ Hospice Friendly Hospitals (2010): Quality Standards for End-of-Life Care in Hospitals, Irish Hospice Foundation, Dublin: 142

account what is known in relation to the person's wishes, feelings, beliefs and values (Randal, 2009).⁵

Advance care planning is based on three core principles in healthcare ethics:

1. Obligation to avoid or minimize harm
2. Provide maximum benefit
3. Respect patient autonomy.

It has developed in response to the recognition that planning options for care with patients leads to:

- Reduction of the effects of complicated grief, stress, anxiety and depression in surviving family members.⁶
- More appropriate management of care (Davison & Torgunard, 2007)
- Higher quality end of life care that is better tailored to the needs and preferences of patients (Hirshman et al, 2007)⁷
- Supported decision making (Sulmasy et al, 2007)
- Improved family satisfaction and supported bereavement experience

1.3 The case for advance care planning: improved patient care

There is an emerging evidence base regarding the role that advance care planning can play in improving the quality of care that can be delivered by health professionals.

The Association for Palliative Medicine (APM) has issued a position statement on advance care planning in which it welcomes national and local initiatives that enable patients to fulfil their wishes for care at the end of their life. The statement says that:

Advance care planning is becoming an increasingly popular approach within end of life strategy and policy documents. It enables patients to express their preferences about their wishes for future care should they lose capacity. The APM supports the more widespread use of advance care planning and advance decisions to refuse treatment. Advance care planning requires sensitive, timely and honest discussion with the patient and those they choose, which may or may not be supported by tools to facilitate and document this. Advance care

⁵ Randall, 2009: The Mental Capacity Act: Implications for Palliative care, EAPC 11th Congress, Vienna, Austria

⁶ Detering et al, 'The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial', *British Medical Journal*, 2010, 340: c1345

⁷ Research has shown that a lack of openness surrounding the fact that a patient is going to die and a lack of planning for their death may act as barriers to achieving high standards of care. In this way, a lack of communication prevents patients and their carers from being able to plan their care (Ellershaw & Ward, 2003)

*planning may be helpful in clarifying decisions to withhold or withdraw treatments...it may also help to achieve a better death for that person.*⁸

The UK End of Life Care Strategy emphasised the importance of advance care planning for better end of life care outcomes.⁹ The first step on the end of life care pathway set out in this strategy is 'discussion as the end of life approaches', involving 'open and honest communication' and 'identifying triggers for discussion'. The NHS tool 'Preferred Priorities for Care' records advance care planning discussions and decisions relating to end of life care.

In Australia, recent research based on older patients in Australia by Detering and Silvester has found that advance care planning 'improves end of life care and patient and family satisfaction and reduces stress, anxiety, and depression in surviving relatives'.¹⁰

The NHS defines advance care planning as: a *process* of discussion and review enabling patients to express and, if they wish, to record views, values and specific treatment choices to inform their future care. It is important to note that it is the discussion and expression of preferences that is key, even if someone does not go so far as to make an advance care directive. In this way, if Think Ahead serves to stimulate discussions about end of life, this will be a gain in itself and will contribute to a change in the culture of 'death denial' in Ireland and a move towards a more open treatment of these issues.

A 2008 report to the US Congress by the Department of Health and Human Services on the subject of advance directives and advance care planning found that advance care planning discussions contributed to increased patient satisfaction without evidence of negative psychological effects.¹¹ When advance care planning is embedded in approaches to care, it has been proven to enable access to palliative care, reduce hospital admissions, and interventionist treatment that may lessen people's quality of life.¹² Similarly, an absence of advance care planning has shown to lead to

⁸ Association for Palliative Medicine (APM) position statement on advance care planning (2008), <http://www.apmonline.org/documents/128499910432102.pdf>

⁹ http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_086345.pdf

¹⁰ Detering, K, The impact of advance care planning on end of life care in elderly patients: randomised controlled trial: *BMJ*2010;340:c1345; Silvester W et al, Advance care planning (ACP), and its impact in the renal unit, *BMJ Support Palliat Care*2012;2:191-192 doi:10.1136

¹¹ [U.S. Department of Health and Human Services, Advance Directives and Advance Care Planning: Report to Congress, Office of the Assistant Secretary for Planning and Evaluation: August 2008](#)

<http://aspe.hhs.gov/daltcp/reports/2008/ADCongRpt.pdf>; Song MK. Effects of end-of-life discussions on patients' affective outcomes. *Nurs Outlook*. May-Jun 2004;52(3):118-125; Walsh RA, Girgis A, Sanson-Fisher RW. Breaking bad news. 2: What evidence is available to guide clinicians? *Behav Med*. Summer 1998;24(2):61-72

¹² Seal, M, Patient advocacy and advance care planning in the acute hospital setting, *Aust J Adv Nurs*. 2007 Jun-Aug;24(4):29-36; Seymour et al, Implementing advance care planning: a qualitative study of community nurses' views and experiences, *BMC Palliative Care*, 2010, 9:4

poorer outcomes in quality of life and lower levels of satisfaction.¹³ There is also evidence that advance care planning improves satisfaction among patients and families in relation to decision-making.¹⁴

While there is as yet relatively limited research in this area,¹⁵ there is an emerging research focus on this topic. One example is ACEL, the International Society of Advance Care Planning and End of Life Care, that is committed to building this evidence base for advance care planning.¹⁶

1.4 Consent and capacity

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. The requirement of informed consent to treatment and care:

- Minimizes harm, e.g. deception, manipulation, assault. The Non-fatal Offences Against the Person Act (1997) asserts that treating someone that has opted to refuse that treatment constitutes a criminal assault of the person
- Maximizes benefit (e.g. adherence, better outcomes)
- Respects autonomy (e.g. choices, priorities, privacy)

Informed consent presupposes voluntariness, information, and **capacity**, (McCarthy, J., M. Donnelly, et al. (2011); O'Shea, E., K. Murphy, et al. (2007).

Measuring capacity is complex, difficult and uncertain. Irish law upholds a presumption of capacity but it is important to note that capacity can fluctuate.

The **functional approach** to assessing capacity focuses on the individual's ability to perform the task of understanding and deliberating on the particular health-care decision being made. The **functional test** determines that 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
- Able to communicate (through talking, sign language etc.) their wishes.

¹³ Lynn, J et al, *End of Life Care and Outcomes. Evidence Report/Technology Assessment No. 110* (Southern California Evidence-based Practice Centre), AHRQ Publication No. 05-E004-2 Rockville MD: Agency for Healthcare Research and Quality, 2004

¹⁴ Caplan, GA et al, Advance care planning and hospital in the nursing home, *Age and Ageing* 2006, 35: 581-585

¹⁵ U.S. Department of Health and Human Services, Advance Directives and Advance Care Planning: Report to Congress, Office of the Assistant Secretary for Planning and Evaluation: August 2008

¹⁶ This paper has been informed by results of controlled searches on CINAHL/Medline, Psychology and Behavioural Science Collection databases and PubMed, as well as open keyword searches on Scirus search engine and Google scholar

The functional approach is applied in the Mental Capacity Act 2005 England and Wales 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; Re C Adult: Refusal of Medical Treatment [1994] 1 WLR 290*.¹⁷

In the case that a person has lost capacity, health professionals have ethical responsibility for deciding on the best clinical approach to their care.

They should do this on the basis of:

- **Any existing advance directive/Power of Attorney:** An advance directive was defined by the Irish Council of Bioethics as a ‘statement made by a competent adult relating to the type and extent of medical treatments she or he would or would not want to undergo in the future should he/she be unable to express consent or dissent at that time’ (2007). An enduring power of attorney is a document drawn up by a competent adult empowering another to make certain decisions on their behalf if capacity is lost. This is currently limited to property and personal care decisions, which does not include health or treatment decisions. The Assisted Decision-Making (Capacity) Bill 2013 now makes provision for the extension of Enduring Powers of Attorney to include healthcare decisions.
- **Substituted judgement standard:** 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)¹⁸
- **Best interests standard:** 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 (Mental Health Act 2001; *In re a Ward of Court [1996] 2 IR 79*; Irish Medical Council 2009).

McCarthy (2011) suggests that professional responsibilities regarding the informed consent process include to:

- Assess capacity in a way that is fair and free from prejudices
- Facilitate people with borderline capacity
- Address broader issues of communication
 - Listen and speak; information is a two-way process
 - Understand emotional and social context
 - Provide honest advice
- Consider consent (and refusal) as a process of repeated engagement; it is not a once-off event.

¹⁷ The Scheme of Mental Capacity Bill of 2008, which was drafted as a result of the recommendations made by the Law Reform Commission, also provided for the functional approach

¹⁸ McCarthy et al, ‘Irish Views on Death and Dying: A National Survey’, *Journal of Medical Ethics*, 2010; 36; 454-458

2. Advance care planning and health professionals

2.1 Understanding and attitudes of health professionals

A major challenge with regard to applying the principles of advance care planning, as well as the implementation of advance care directives, is a lack of understanding and knowledge among health care professionals regarding their role and responsibilities in this area.

Research carried out in Ireland in 2006 found that 27% of consultant physicians had experience of caring for a patient with an advance care directive.¹⁹ It is hoped that the guidelines that are expected to follow the National Consent Policy (outlined below in Section 3.2.1) will work to counter this lack of understanding.²⁰

With regard to attitudes, while the majority of research on the attitudes of health professionals to advance care planning finds largely positive responses to the concept, concerns have been reported by some health professionals in relation to their perceived capacity to have these conversations with patients and the communication skills involved.²¹

US research has found that the attitude of health professionals will often determine the nature of the end of life care that is provided, as well whether or not related discussions and decision-making processes are undertaken.²²

In terms of employee well-being and job satisfaction among health care professionals, research has found that increased job satisfaction is an associated gain with increased quality end of life assurance that is provided by advance care planning process.²³

More research is required on the levels of confidence and competence that health professionals have in having these conversations as well as the skills required to both initiate and respond to discussions.

2.2 Professional ethical standards

There is growing acknowledgment among medical professionals and their regulatory bodies of the importance of patient autonomy and the obligation of medical professionals to respect and implement their patients' wishes. This is within the parameters of the law: while people have the legal right to refuse treatment, they cannot demand treatment.

A person's autonomy relates to the way they have lived their life and the things that are most important to them: '[A] person's autonomy is found also in how they express their sense of self, in

¹⁹ Butler et al, 'Dissatisfaction with Do Not Attempt Resuscitation Orders: A nationwide study of consultant physicians practices', *Irish Medical Journal*, 2006

²⁰ At the time of writing, this policy remains in draft form as it has not yet been approved by the HSE Board

²¹ Seymour et al, Advance care planning for patients with inoperable lung cancer, *International Journal of Palliative Nursing* 2006, 12: 172-179

²² Bach JR. Threats to "informed" advance directives for the severely physically challenged? *Arch Phys Med Rehabil*. 2003;84(4 Suppl 2):S23-28

²³ Seal, M, Patient advocacy and advance care planning in the acute hospital setting, *Aust J Adv Nurs*. 2007 Jun-Aug;24(4):29-36

their relationships with those important to them, and in their values and preferences' (Nuffield 2009: 74).

The **Irish Medical Council's Guide to Professional Conduct and Ethics (7th ed, 2009)** acknowledges the role of the doctor in assisting people to deal with the reality of death and the importance of effective and sensitive communication with patients so that they have a clear understanding of what can and cannot be achieved in relation to their own care. The Irish Medical Council's Guide also advises doctors that a patient's advance treatment plan should be respected if it represents an informed choice by the patient at a time when they had capacity, it covers the relevant situation which has now arisen and there is no evidence that the patient has changed their mind.

The Irish Medical Council holds 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
- The decision covers the situation that has arisen, and
- The patient has not changed their mind.

If there is doubt about the existence of an advance treatment plan, the patient's capacity at the time of making the treatment plan or whether it still applies in the present circumstances, the treating doctor should make treatment decisions based on the patient's best interests. In making these decisions the Medical Council calls for doctors to consult with any person with legal authority to make decisions on behalf of the patient and the patient's family if possible.

An Board Altranais is currently in the process of reviewing its code of conduct and this will likely include issues of care planning and nurses' role in initiating and facilitating patients' care plans.

Momentum for Change

3.1 International policy context

3.1.1 International rights instruments

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.²⁴ The statement recommended that Member States promote self-determination for adults in the event of their future incapacity by means of powers of attorney and advance directives.

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.

²⁴ *CM/Rec(2009)11*

3.1.2 Other legal jurisdictions

Advance care directives enjoy legal status in **other jurisdictions** such as:

COUNTRY	LEGAL SITUATION
US	The US has led the trend regarding policy development to enhance patient autonomy in this area. ²⁵ 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. The Mental Capacity Act was passed in 2005, allowing 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 are considered to be legally binding in Scotland under common law. Under the <i>Adults with Incapacity (Scotland) Act 2000</i> 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. ²⁶
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

²⁵ Ulrich, LP. *The Patient Self-Determination Act: Meeting the Challenges in Patient Care* (Washington: Georgetown University Press, 2001)

²⁶ Wareham P et al, *Advance directives: the New Zealand context* (Nurs Ethics. 2005 Jul;12(4):349-59)

	the Canadian Medical Association
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.

3.1.3 International advance care planning initiatives

In addition to international examples of the legal recognition of advance care directives, as mentioned above, there has also been recognition internationally that the effective storage of personal information regarding patients' preferences is vital in the delivery of quality care. In this context, there is significant international momentum behind developing systems to record people's health preferences and other information.

COUNTRY	ADVANCE CARE PLANNING INITIATIVE
US	<p>The U.S. Living Will Registry has been storing advance directives since 1996. The Registry electronically stores the documents and makes them available to hospitals and health care providers.</p> <p>Medicare in the US has also developed end of life orders called POLST (physician order life sustaining treatment). There are state-specific versions of the POLST form.</p> <p>The Conversation Project, launched in 2010, is an initiative dedicated to helping people talk about their wishes for end-of-life care.²⁷</p> <p>Honoring Choices is a programme developed in Minnesota providing professionally facilitated advance care planning conversations for members of the public, as well as training for health care staff.²⁸</p>
UK	<p>The NHS National End of Life Care programme has developed a guide for health and social care staff in the importance of assessing a person's capacity to make particular decisions about their care and treatment and of acting in the best interests of those who are assessed as lacking capacity to make these decisions.²⁹</p>

²⁷ <http://theconversationproject.org/>

²⁸ www.HonoringChoices.org

²⁹ <http://www.endoflifecareforadults.nhs.uk/publications/pubacpguide>

	<p>Dying Matters³⁰ was set up in 2009 by the National Council for Palliative Care (NCPC). It is a broad based and inclusive national coalition of 28,000 members, which aims to change public knowledge, attitudes and behaviours towards dying, death and bereavement and to encourage conversations about these issues. Its members include organisations from across the NHS, voluntary and independent health and care sectors (including hospices, care homes, charities supporting old people, children and bereavement); social care and housing sectors; a wide range of faith organisations; community organisations; schools and colleges; academic bodies; trade unions; the legal profession and the funeral sector.</p>
Northern Ireland	<p>The Northern Irish Public Health Agency is engaged in a regional initiative called Living Matters and Dying Matters. The aim of the initiative is to develop a regional approach to promoting open discussion about palliative and end of life care, aimed at all members of the public and the health and social care sector. A Regional Implementation Board, representative of key stakeholders, has been established with a remit to ensure the recommendations contained within the 'Living Matters, Dying Matters' Strategy and Priorities for Action 2009/10, are developed and embedded into practice. The Regional Implementation Board has three work streams: Education; System and Process; and Raising Awareness - the raising awareness subgroup, comprises PHA, all five Health and Social Care Trusts, Patient and Client Council, voluntary, charity and community sector will engage across public and professional communities, working with and through already established groups.</p> <p>The Royal College of General Practice established an end of life care group in 2011. The group is in the process of developing a patient passport which was included as an objective in the End of Life care strategy. Dr Aine Abbott was appointed as a Clinical lead GP in January 2011 and has been funded part-time for 2 years to develop the patient passport. There is not yet a fully evolved tool but a basic blueprint has been produced which is going to be piloted and modified over the next six months. The hope is that a group of clinicians will pilot each version: dementia; neurodegenerative conditions which don't immediately impact on mental capacity; cancer; children with life limiting illness; and long-term co-morbidities. The version for dementia is to be piloted first.</p>
Scotland	<p>Anticipatory care planning is one of the five priorities of <i>Living and Dying Well: Building on Progress</i> and patients are officially encouraged to create anticipatory care plans.³¹ The electronic sharing of these plans among clinicians is currently under development.³² The Government has also developed an ACP toolkit which includes a conceptual framework, triggers for creating anticipatory care plans, and practical guidance in this regard, including core components and a sample plan.³³</p>

³⁰ <http://www.dyingmatters.org/>

³¹ *Living and Dying Well: Building on Progress* was published in 2011 following the 2008 national action plan for palliative and end of life care, *Living and Dying Well*

³² <http://www.scotland.gov.uk/Publications/2010/04/13104128/1>

³³ These resources are available at: www.scotland.gov.uk/livinganddyingwell

Canada	Speak up is a Canadian initiative aimed at helping health professionals and governments to better understand how advance care planning practices can improve care and address the many issues the health system faces in delivering services to an aging population. ³⁴
Australia	Respecting Patient Choices comes from the Australian <i>National Palliative Care Program</i> and is supported by the Australian Government Department of Health and Ageing . It was introduced in 2002 to provide guidelines and training on having advance care planning discussions. It includes advance care planning resources both for members of the public and also for training for health care professionals ³⁵
New Zealand	In 2009 the Ministry of Health published a consultation document, <i>Advance Care Planning: An Overview</i> , which was intended to for the basis of standardised information and formalised guidelines for health professionals in the area of advance care planning. ³⁶ Another document, <i>Advance Care Planning for Adults: Planning for your future care</i> , was published by the Ministry to inform and guide patients and their families in relation to these issues.

3.2 Irish policy context

3.2.1 Policy commitments

There have been several **policy statements** supporting the concept of advance care planning.

i) HSE:

While there is no national policy and guidelines in this area, care planning is nonetheless an activity carried out within the health services, albeit with significant variation. Some hospitals have adopted the Liverpool Care Pathway, although feedback on its application has been very varied. Acute and community hospitals are also looking at care pathways more generally.

In terms of **documentation**, hospitals use **health care records** for every patient and these can perform a care planning function. Health care records are not available to community staff but discharge letters and test results are sent to GPs. Health care records include information related to health matters and relevant treatment plans.

A goal of the **HSE Strategic Plan for 2008-13** 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’ (p.14). 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’ (*National Strategy for Service User Involvement in the Irish Health Service 2008-13: 14*).

³⁴ <http://www.advancecareplanning.ca/>

³⁵ These resources are available at: <http://www.respectingpatientchoices.org.au/>

³⁶ <http://www.moh.govt.nz/moh.nsf/indexmh/advance-care-planning-consultation>

The HSE's Quality and Clinical Care Directorate has developed a wide range of National Clinical programmes and one of these is the **Palliative Care Programme**. A key work stream of the Palliative Care Programme is advance care planning. Initially this will focus on older people with life-limiting illnesses and the plan is 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'.³⁷

ii) Department of Health: The Department of Health **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;
- Individual care plans with a focus on personal goals and outcomes;

iii) 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 published in 2012 and was approved by the HSE Board in April 2013.

The policy acknowledges the fact 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.³⁸ 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 show 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.

³⁷ <http://www.hse.ie/eng/about/Who/clinical/natclinprog/pallcareprog.html>

³⁸ National Consent Advisory Group, National Consent Policy, May-June 2012, Part 4 – Do Not Attempt Resuscitation (DNAR)
http://www.hse.ie/eng/about/Who/qualityandpatientsafety/Patient_Safety/National_Consent_Advisory_Group/ncag4.pdf

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’.³⁹

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.⁴⁰

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’.⁴¹

Finally, 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.⁴²

iv) HIQA

HIQA Standard 16 calls for nursing homes to engage with residents in relation to planning their end of life care and preferences.⁴³ It is important to note that there is no specific guidance in the standards for residential care settings for timing of discussions and any consequent documentation regarding residents’ wishes and choices regarding end of life care. This is leading to the development of inconsistent approaches.

³⁹ National Consent Advisory Group, National Consent Policy, May-June 2012, Part 4 – Do Not Attempt Resuscitation (DNAR): 9

⁴⁰ National Consent Advisory Group, National Consent Policy, May-June 2012, Part 4 – Do Not Attempt Resuscitation (DNAR): 19

⁴¹ National Consent Advisory Group, National Consent Policy, May-June 2012, Part 4 – Do Not Attempt Resuscitation (DNAR): 12

⁴² National Consent Advisory Group, National Consent Policy, May-June 2012, Part 4 – Do Not Attempt Resuscitation (DNAR): 14

⁴³ 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

3.2.2 Political support

There has been political recognition of a movement in Ireland for more patient autonomy with increased awareness among members of the public of their rights in relation to treatment and care.

There was strong political support expressed at the launch of Think Ahead at the Forum on End of Life in October 2011 by An Taoiseach Enda Kenny who said that:

'The Think Ahead initiative helps prevent shock, helps avoid confusion...by encouraging us to think, talk and tell. Think Ahead 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 Taoiseach went on to say that:

'Putting the patients' choices and concerns at the centre of health services is a key aim of and driver for Government's reform programme for our health services. The end of life is no less precious than any other stage. In fact in many ways it is even more so. Which is why when we're at that stage we are entitled to dignity and respect, to have our wishes and concerns taken on board. The new 'Think Ahead' form is a key part of this new approach.'

Government deputies and senators have also been extremely supportive of Think Ahead during the pilots in Limerick and Louth from September to November 2012.

There have been several statements made by politicians in the Dail in relation to advance care directives. In June 2012, Deputy Liam Twomey's Advance Healthcare Decisions Bill came before the Dail in the form of a private member's bill. While there was widespread support for the objectives of the bill, it was withdrawn by Deputy Twomey following an undertaking by the Minister for Health James Reilly that provision for advance care directives would be included in the Assisted Decision-Making (Capacity) Bill.

During the debate of Deputy Twomey's bill the Minister said:

'There is increasing recognition that advance health care directives can empower patients by giving them greater control over their treatment and care decisions. They are also regarded as an important instrument in fostering a patient centred health care model and strengthening partnerships between individuals and their health care providers. In this respect, I recently attended an informal meeting of European Ministers for Health in Denmark at which the issue of patient empowerment was the main focus of discussion'.⁴⁴

1.1 Legal framework

While there is currently no Irish legislation governing advance care directives, they are legally binding in Ireland according to Irish law and to international law to which Ireland is bound. The decision of the Irish Supreme Court in *Re a Ward of Court (No 2)* [1996] 2 IR 79 says that advance

⁴⁴ Minister for Health's response speech to Advance Health Decisions Bill at Second Stage in the Dáil, Friday 18 June 2012

care directives are recognised by Irish law, provided that the author was competent and that the directive was specific to the patient's current situation.

Think Ahead is a tool designed to ensure that people have an understanding of their legal rights to refuse care and to express preferences.

3.3.1 Law Reform Commission Report

The Think Ahead project comes in the context of the **Law Reform Commission's Report, Bioethics: Advance Care Directives**, published in September 2009.

The report made 42 specific recommendations:

- 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.

3.3.2 Assisted Decision Making (Capacity) Bill

In March 2013, a commitment was made by Government that provision for advance directives would be included in the **Assisted Decision Making (Capacity) Bill** at Committee Stage. The enactment of this legislation and its inclusion of provision for advance care directives would go toward fulfilling Ireland's obligations under the **2006 UN Convention on the Rights of Persons with Disabilities** and the Council of Europe's Recommendation on Advance Directives.

The Law Reform Commission's draft Bill on Advance Care Directives (2009) was set in the context of the proposed Assisted Decision-Making (Capacity) Bill which provides for a functional approach to the assessment of capacity, sets out principles that must be followed for those who lack capacity and provides an overarching modern framework for the protection of people who lack capacity. It would be 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.

3.3.3 Health Information Bill

The potential storage of advance directives, and their accessibility by relevant authorities, will be influenced by the forthcoming Health Information Bill. At the time of writing it is not known when this Bill will be published.