Advance Healthcare Directives: Friend or Foe?

Lorna M. Murphy
Royal College of Surgeons in Ireland, lornamurphy@rcsi.ie

Citation
Creative Commons Licence:

This work is licensed under a Creative Commons Attribution-Noncommercial-Share Alike 4.0 License.
Advance Healthcare Directives: Friend or Foe?

Lorna Murphy
Department of General Practice
RCSI

A dissertation submitted in partial fulfilment of the requirement for the Masters in Health Care Ethics and Law

Supervisor: Dr. Joan Cunningham

July 2015
Declaration

I declare that this thesis, which I submit to RCSI for examination in consideration of the award of a higher degree, MSc in Healthcare Ethics and Law, is my own personal effort. Where any of the content presented is the result of input or data from a related collaborative research programme this is duly acknowledged in the text such that it is possible to ascertain how much of the work is my own. I have not already obtained a degree in RCSI or elsewhere on the basis of this work. Furthermore, I took reasonable care to ensure that the work is original, and, to the best of my knowledge, does not breach copyright law, and has not been taken from other sources except where such work has been cited and acknowledged within the text.

Signed

__________________________________________

Student Number  131125231

Date  24th July 2015
## Table of Contents

Declaration.................................................................................................................... 2  

IP Declaration .............................................................................................................. Error! Bookmark not defined.  

Table of Contents........................................................................................................ 4  

List of Abbreviations .................................................................................................. 6  

List of Figures ............................................................................................................. 7  

Abstract....................................................................................................................... 8  

Acknowledgements ..................................................................................................... 9  

Dedication ................................................................................................................... 11  

Introduction ................................................................................................................ 12  

Chapter 1 ..................................................................................................................... 15  

1.1 Why did Advance Healthcare Directives develop? ............................................. 15  

1.1.1 What is an advance healthcare directive? ...................................................... 15  

1.1.2 Who wants advanced healthcare directives? And Why? ......................... 23  

1.1.3 Advance Healthcare Plans vs Advance Healthcare Directives. ................ 28  

Chapter 2 ..................................................................................................................... 30  

2.1 Ethical arguments concerning Advanced Healthcare Directives.... ............ 30  

2.1.1 Autonomy and Other Future Self................................................................. 30  

2.1.2 Personhood and Personal Identity Theory .................................................. 32  

2.1.3 Capacity and Advance Healthcare Directives ............................................ 34  

2.1.4 Cultural influences and advances in medical treatments......................... 36  

2.1.5 Medical advice and medical treatments ....................................................... 40  

Chapter 3 ..................................................................................................................... 44  

3.1 How are the laws being interpreted? ................................................................. 44  

3.1.1 Advance Healthcare Directives vs Enduring Power of Attorney ............ 44  

3.1.2 What’s happening in the US? ...................................................................... 47  

3.1.3 Can we look to UK for guidance? ................................................................. 54
3.1.4 Development of Advance Healthcare Directives in Ireland...... 61
3.1.5 Our new proposed legislation............................................. 61

Chapter 4..................................................................................................... 74

4.1 How can we guide implementation of the new legislation? .......... 74
  4.1.1 Guidelines – Code of Practice............................................... 74
  4.1.2 Central database of registered advanced care directives....... 75
  4.1.3 Surveys conducted in Ireland.............................................. 76
  4.1.4 Promoting and discussing advance healthcare directives...... 84

Conclusion ................................................................................................... 89

Recommendations ....................................................................................... 92

Appendices .................................................................................................. 94

Samples of Advance Care Directives ....................................................... 94
  Computer based – Advance Directives from Penn State College of
    Medicine................................................................................................. 94
  Think Ahead – Sample Form............................................................... 116

Bibliography ............................................................................................... 146

Final Word Count: 24,972
## List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACD</td>
<td>Advance Care Directive</td>
</tr>
<tr>
<td>ACP</td>
<td>Advance Care Plan</td>
</tr>
<tr>
<td>AD</td>
<td>Advance Directive</td>
</tr>
<tr>
<td>AHD</td>
<td>Advance Healthcare Directive</td>
</tr>
<tr>
<td>ANH</td>
<td>Artificial Nutrition and Hydration</td>
</tr>
<tr>
<td>CPR</td>
<td>Cardiopulmonary Resuscitation</td>
</tr>
<tr>
<td>DNAR</td>
<td>Do Not Attempt Resuscitation</td>
</tr>
<tr>
<td>DNR</td>
<td>Do Not Resuscitate</td>
</tr>
<tr>
<td>GP</td>
<td>General Practitioner</td>
</tr>
<tr>
<td>HCP</td>
<td>Healthcare Professional</td>
</tr>
<tr>
<td>HFH</td>
<td>Hospice Friendly Hospitals</td>
</tr>
<tr>
<td>HFHP</td>
<td>Hospice Friendly Hospitals Programme</td>
</tr>
<tr>
<td>HSE</td>
<td>Health Services Executive</td>
</tr>
<tr>
<td>ICB</td>
<td>Irish Council for Bioethics</td>
</tr>
<tr>
<td>ICU</td>
<td>Intensive Care Unit</td>
</tr>
<tr>
<td>IHF</td>
<td>Irish Hospice Foundation</td>
</tr>
<tr>
<td>IMC</td>
<td>Irish Medical Council</td>
</tr>
<tr>
<td>LRC</td>
<td>Law Reform Commission</td>
</tr>
<tr>
<td>MND</td>
<td>Motor Neurone Disease</td>
</tr>
<tr>
<td>PSDA</td>
<td>Patient Self-Determination Act</td>
</tr>
<tr>
<td>PVS</td>
<td>Persistent vegetative state</td>
</tr>
</tbody>
</table>
List of Figures

Fig 2.1.3.1 Causes of deaths in Ireland in 2012  34
Fig 2.1.3.2 Place of death in Ireland in 2012  35
Abstract

**Objectives** - This thesis proposes the question, Advance Healthcare Directives – Friend or Foe? Is it a good thing or a bad thing to have an advance healthcare directive?

**Ethical and legal considerations** - I introduce the concept of an advance healthcare directive and why they developed. They started in the US where they are called ‘living wills’. They aim to promote patient autonomy and self determination in advance of the loss of capacity. Ethical arguments about making decisions for a ‘future self’ have been balanced with legal arguments for PVS patients being allowed to die by refusing treatments. I have shown that there may be many obstacles and barriers to the implementation of advance healthcare directives. By using the internet with websites to provide information and guidance in preparing an advance healthcare directive, more and more people are becoming aware of them. New procedures, guidelines and laws have allowed more protection for vulnerable patients while at the same time promoting advance healthcare directives as a means of extending patient autonomy into the future.

**Conclusion** – Many of the initial problems of advanced care directives have been recognised and addressed in various guides and laws from the US and UK. Here in Ireland we still lag behind in the distribution of information and raising public awareness around the whole topic of death and dying but especially in this aspect of preparing an advance healthcare directive. Legally binding instruments may make preparing an advance healthcare directive more cumbersome but they allow for greater certainty that the advance healthcare directive will be judged valid and applicable and thus implementing the patients’ decisions. I conclude that advance healthcare directives are our friends, though as in any good relationship, it may be a bit complex at times but it is worth the effort.
Acknowledgements

I would like to thank a number of people who have supported me in my efforts to complete this dissertation for my MSc in Healthcare Ethics and Law.

Firstly, I would like to thank RCSI

a) the HR department for their encouragement to me to develop and expand my skills not only within my current working environment but also to think outside the box and develop my skills in diverse and varied ways,

b) my head of department, Chief Librarian, Kate Kelly, who has provided encouragement and support for my time away from work to study and prepare for exams, and write this dissertation,

c) the financial support from RCSI who provide discounts to members of staff to attend various, interesting and challenging courses like this one.

d) All the lecturers, programme administrators and of course our programme director, Prof David Smith, for all their support throughout our two years attending this Masters course. They were always a source of inspiration and support, always ready with advice when needed, without which this important and very special course would not exist.

e) I do not want to forget my classmates and colleagues who were there throughout this two year journey. Even though each of us were struggling with these new challenges in our own way we were always able to offer advice and support to each other on our facebook page or at our monthly lectures. It was great to get to know you all especially Aisling as our 1st year class representative and social organiser.

I would like to thank Dr. Joan Cunningham, my dissertation supervisor, who was always ready with advise to help me focus on my topic, with prompt
responses to any and all queries, and of course with helpful introductions to specialists in the field to help bring the 'voice of experience' into this dissertation.
Dedication

I would like to dedicate this dissertation to my three sons, Cillian, Tiarnán and Patrick, who have always provided me with my motivation to expand my horizons and opportunities for my future. For picking up the slack at home when chores were not always done in their usual fashion. I thank them for their patience and support throughout this busy period with all the extra work and study hours which took me away from them.

I would also like to dedicate this dissertation to my mother, Colette, who has had to put up with me disappearing to work, to the library, to college while I progressed through my studies this past two years. She has always been a source of strength and steadfast belief in me throughout my life. I love you Mum, always.
Introduction

I was introduced to this concept of advance healthcare directives and the concept of end-of-life plans while studying this MSc course on Healthcare Ethics and Law. It was initially a difficult topic to get my head into. I must admit that thinking about death and dying, like for most of us, is not a topic I liked to delve into for very long or in great depth. However the module had to be tackled and I rose to the challenge. After the initial reluctance I found the topic intriguing. Death like birth only happens to us once. I can make so many plans for the arrival of a new baby, preparing a room, cot, clothes, whether the delivery will be at home or in the hospital, so why am I so reluctant to prepare for a good death? Of course the older I get the more I may think about death and what will happen to those I leave behind. The main thing I have come to appreciate from my research into this topic is how much better it can be, not just for me but also for my family and friends, if I prepare for death a little more. It is not just death though that is covered here it is more about how I may die, and how I am treated before I die. Advance healthcare directives cover decisions I wish to make for my medical treatments for the time when I may lack capacity. In actual fact it may not even be about death at all as I may recover from the accident or illness that caused me to lose capacity. But there are the occasions, which I may wish to consider, where I have no chance of recovery. What type of treatment do I want then? How much treatment and for how long?

I will review how advance healthcare directives developed. They started in the US and have become widely used all around the world. They have evolved and changed over the years with new legislation and new ethical arguments influencing the directions different countries like the US and UK have taken.

Scope and Limits

I have limited the scope of this thesis due to time and constraints on the number of countries I can cover.

The limitations or focus of the thesis is.
1. Advanced care directives – as currently applies to the US and UK. The rest of Europe or Asia is excluded.

2. Difference between advanced care plans (medical consultation – with team of healthcare professionals, patients and their families) and advanced care directives (no legal or medical consultation required)

3. Making advanced healthcare decisions for oneself for the future. As the Irish Council for Bioethics did in their report we will exclude parents making advanced care directives for their children or pregnant woman who may be making a decision which would also affect their unborn baby.

4. Looking at various legal cases in the US, UK and Ireland which have been influential in the development of advance healthcare directives.

5. Excluding cases of incapacity due to mental illness as this would be better covered under a discussion of the Mental Health Act 2001 and its powers of decision making and specifically on involuntary detention.

This thesis will review the ethical arguments about making decisions for your ‘future self’ and extending patient autonomy into the future. I will also compare the legal instruments, an enduring power of attorney and an advance healthcare directive, which allow an individual to pass on to another person the authority to make decisions on their behalf.

How have we been influenced by the laws made in the US and in the UK? I will focus on the new proposed legislation in Ireland and how it may be implemented. I will look at the current guidelines available from HSE and compare them to the UK guidelines. What guidelines are available to GPs and other healthcare professionals? I will look at the many studies and surveys carried out by the Irish Hospice Foundation in promoting advance healthcare plans and directives in championing patient autonomy and dignity in death. The development of and promotion of tools like ‘Think Ahead’, which encompasses more than just advance healthcare directives but is a
simple, well laid out document to assist anyone to ‘put their affairs in order’, financial, legal as well as medical.

I will look at the problems with advanced care directives, for the public, for medical professionals, for the courts in interpreting the patient’s wishes.

Advance healthcare directives have to be made available to healthcare professionals if they are to be implemented so we will also look at the central national register of advance healthcare directives which has been developed in the US.
Chapter 1

1.1 Why did Advance Healthcare Directives develop?

1.1.1 What is an advance healthcare directive?

Advance healthcare directives have been described by several Irish agencies and international authorities, some of their definitions include

1. The Irish Council for Bioethics defines it as ‘a statement made by a competent adult relating to the type and extent of medical treatments he or she would or would not want to undergo in the future should he/she be unable to express consent or dissent at the time’. (Irish Council for Bioethics, 2007)

2. The Irish Law Reform Commission describes it as ‘an advance 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’. (Irish Law Reform Commission, 2009)

3. The Council of Europe defines an advance directive as ‘instructions given or wishes made by a capable adult concerning issues that may arise in the event of his or her incapacity’.

The objectives of advance healthcare directives are to

1. Facilitate the provision of healthcare
2. Protect patient’s welfare and autonomy
3. Protect the healthcare professionals from liability.

The Council of Europe through the Parliamentary Assembly have also put forward resolutions to ‘protect human rights and dignity by taking into account previously expressed wishes of patients’ (Council of Europe, 2012) in their Recommendation CM/Rec (2009)11 (Council of Europe, 2009) which lays down a number of principles to guide member states in regulating advance directives. The Council of Europe deals with advance instructions with regard to property and legal matters as in an enduring power of attorney as well as directives in relation to health and welfare. For the purposes of my discussion
here I will concentrate on the advance directives dealing with decisions of healthcare and welfare of the patient.

The recommendation of the Law Reform Commission was to use the term ‘advance care directive’ to encompass not only healthcare decisions with regard to treatments in the future but also to ‘deal with advance expression of wishes of an individual in a health care or wider care setting’ (Irish Law Reform Commission, 2009). However the new proposed legislation uses the term ‘advance healthcare directive’ and leaves it to the directive-maker to decide which care decisions to put into their directive.

The proposed new Irish legislation (Assisted Decision-Making Capacity Bill 2013) introduces the patient’s trusted friend - a ‘designated healthcare representative’ who may be assigned the legal authority to make decisions on behalf of the patient when the patient is no longer capable of making these decisions for themselves. At a public meeting about advance healthcare directives in 2014, Dr. Siobhan O’Sullivan, the Bioethics Officer with the Department of Health, outlined the proposed new legislation (O’Sullivan, 2014). The legislation will include some safeguards concerning the designated healthcare representative with the requirement for witnesses to sign it. There should be two adult witnesses, one of whom should not be in a position to inherit from the patient.

The development of respect for patient autonomy and patient consent policies in many countries has brought about a public awareness of patient rights to make decisions about their own healthcare. Advances in medical care have allowed patients to recover from serious illnesses and injuries. There are now new procedures in treatment for illnesses that would have been fatal before. New drugs have provided patients with terminal illnesses respite from the symptoms and allowed a much higher quality of life for longer than ever before. Examples are the improvements and survival rates for many cancers, heart conditions, AIDS and recently the new drugs to combat Ebola. Many patients are living well with many chronic and critical conditions but there is always the inevitable decline. So we now have a
dilemma of facing decisions about when to stop the life-prolonging measures in favour of comfort care and providing the best quality of life possible. (Sjoding and Cooke, 2015). It is possible for patients to be kept alive in many states of incapacity, like persistent vegetative state, locked in syndrome or even to prolong life in many terminally ill cases. Whilst some patients appear to want any available treatment that can prolong their life at any cost, there is a growing body of society who see these attempts to prolong life as lacking in human dignity and respect. They want to make their wishes known in advance and to feel confident in the knowledge that a fate of being kept alive without human dignity will not befall them. In the following cases I will show the development of laws to support advance healthcare directives starting in the United States to support patients’ rights and autonomy. ‘Living Wills’ provide instructions for patients’ healthcare decisions if they lose capacity in the future.

First legislation for advanced care directives started in the US. The development of legislation to cover a legal framework for advanced care directives started in the US with the US Supreme Court decision in the Re Quinlan case in 1976 (Fine, 2005) allowing for the withdrawal of artificial respiration for a patient in a persistent vegetative state.

Three cases in particular highlighted the need for legislation
   a) to support the patient’s rights and dignity,
   b) to support families rights
   c) to support and protect professional healthcare providers in clinical decisions

These cases started with
1. Karen Quinlan who stopped breathing and went into a persistent vegetative state or coma in 1975 after a respiratory arrest. (1976a) Her parents requested for her to be taken off the artificial ventilator so that she might be allowed to die. The decision by the New Jersey Supreme Court was based on the right to privacy. The court found that
families were adequate surrogates to make healthcare decisions for incapacitated patients. They also found that quality of life was a legitimate consideration in decisions concerning life-sustaining treatments. The court put forward the concept of a ‘prognosis committee’ to assist in such cases to help avoid judicial measures being sought. This concept has developed into what we know today as a ‘clinical ethics committee’. After the ventilator was removed in 1976, Karen lived on for a further 10 years with artificial nutrition and hydration (ANH) before dying of pneumonia.

2. Nancy Beth Cruzan was seriously injured in a car crash in 1983. She was in a persistent vegetative state and her parents requested the removal of ANH to allow her to die. (1990a) The heated and long drawn out debate was not about Nancy’s ‘right to die’ or about her quality of life but about the right of others to take her life by allowing her to die by starvation. After many court hearings in Missouri before the probate court and the Missouri Supreme Court, the US Supreme Court finally ruled in 1990 for the withdrawal of ANH based on the argument that patients have a fundamental right to refuse life sustaining treatment. People who knew her came forward to provide sufficient evidence that Nancy would not have wanted to be kept alive in a vegetative state.

3. Terri (Theresa Marie) Schiavo had a cardiac arrest in 1990. In 1994 after 4 years in a persistently vegetative state and completion of various therapies Terri was placed in a nursing home. In 1998, eight years after Terri entered the persistent vegetative state and 6 years after all experimental and rehabilitative treatments were complete, her husband requested a court to allow the removal of her feeding tube, arguing that she would not want to be kept alive in a persistent vegetative state. (2005a) The court ruled, after hearing testimony for almost two years, that there ‘was clear and convincing evidence that Terri was in a permanent vegetative state and that she would choose to discontinue life-prolonging medical care’. Due to family disagreement between her husband and her parents the case went
through many courts and appeals. Terri’s parents argued for the preservation and sanctity of life. The debate around life-sustaining treatments for PVS patients gained extensive coverage both national and international, reflecting the many diverse opinions around this complex issue. In total there were rulings by 19 judges and 6 different courts, all of which decided in favour of Terri’s husband. Terri’s feeding tube was finally removed in March 2005 and she died painlessly from dehydration shortly afterwards. This case highlighted the advantages of having an advance healthcare directive in avoiding not only the long drawn out court battles but the distress and division which may occur in families who cannot agree on the treatment options for their loved one.

These cases highlighted the lack of legislation on advance healthcare directives. The Quinlan case was followed very quickly by the first laws supporting advanced care directives or ‘living wills’ enacted in the State of California in 1976 (1976b). After the Cruzan case the Patient Self-Determination Act (PSDA) 1990 was enacted by the United States Federal Congress(1990b) protecting patient’s rights to accept or reject medical or surgical treatments while competent for the situation in the future where they would become incompetent to make such decisions themselves.

Legal cases in Ireland dealing with life and death decisions.
The case of a Ward of Court in Ireland which started in 1996 concerned a 46 year old woman who had spent 24 years in a near persistent vegetative state (near PVS). In 1972, when the ward was only twenty-two years old, she underwent a minor gynaecological operation. During the operation she suffered three cardiac arrests and was left with serious brain damage. In October 1974, she was made a Ward of Court. She was fed initially through a nasogastric tube which after 20 years was replaced with a gastrostomy tube. In 1996 her mother applied to the courts for direction on her daughter’s care. It was argued that it was the family’s prerogative to decide whether the medical treatment should be withdrawn as it would comply with the family’s inalienable and imprescriptibly rights guaranteed under the Irish Constitution.
The Supreme Court held that it was in the woman’s best interest to withdraw the artificial nutrition and hydration (ANH) and allow her ‘to die in accordance with nature with all such palliative care and medication as is necessary to ensure a peaceful and pain-free death.’ They also declared that ‘the non-use of antibiotics for treatment of infections, other than in a palliative way to avoid pain and suffering, was also lawful.’ Due to the religious nature of the ethos of some Irish hospitals, the court also ordered that the family could make arrangements to admit her to a facility that would not regard the withdrawal of ANH to be contrary to their code of ethics. The institution, which had been caring for the Ward, had replied to the claim made by the family to the Courts that they should not be ‘required to do any act contrary to its philosophy and code of ethics and there is no legal basis for such requirement’. This case highlights the effect of differences, not between family members, but between the family and the healthcare professionals looking after a patient. It took the Supreme Court to decide on ‘clear and convincing’ arguments put before it to judge, in their position of parent, ‘parens patriae’, and in the best interests of the Ward to allow the termination of ANH and allow a natural, peaceful and pain-free death.

The case of Fitzpatrick v FK (2008) highlighted the question of capacity to refuse treatment and especially the consequences not only to the patient herself (in this case a refusal of a blood transfusion) and its effect on her newborn son. Judge Laffoy concluded that Ms K’s capacity was impaired to the extent that she did not have the ability to make a valid refusal to accept a blood transfusion.

Development of advance healthcare directives in Ireland
In 2000 the Irish Council for Bioethics was founded as an advisory body for the government. In 2007 the Council published a report on Advanced Healthcare Directives, ‘Is it time for Advance Healthcare Directives? Opinion’ (Irish Council for Bioethics, 2007) which examined the ethical and legal issues associated with such directives. The Council offered a balanced and
objective overview of the feasibility, format, content and implementation of advance healthcare directives. Their report hoped to facilitate further discussion and debate on this important issue.

The Irish Law Reform Commission also published a report in 2009 on ‘Bioethics: Advance Care Directives’ (Irish Law Reform Commission, 2009). The report concentrated on the ‘interaction between law and bioethics’. The report set out its recommendations which formed the basis for new legislation entitled ‘Assisted Decision Making (Capacity) Bill - 2013’ (Department of Justice and Equality, 2013) which not only covers Advanced Care Directives but also introduces the ‘designated healthcare representative’ who may assist in the decision making process or help interpret the patient’s wishes and communicate them to the healthcare professionals looking after the patient.

These advances in legislation came after several cases before the courts which would have been much more easily adjudicated if there had been an advance healthcare directive in place. These cases are highly distressing for the family, friends and all the healthcare providers involved. Due to their publicity they help increase public awareness of patient rights and provide additional momentum to the recognition and development of patient decision making in contemporaneous as well as future treatment options. Even without legal standing already there are many hospitals in Ireland who have signed up to the Irish Hospice Foundation ‘Hospice Friendly Hospitals Programme’, which provides information and guidance in a ‘End-of-Life Toolkit’ to assist staff in care planning and advance care planning (Irish Hospice Foundation, 2007). This HFH programme has been supported by our major hospitals like Mater Misericordiae University Hospital, Cork University Hospital, Beaumont Hospital and the children’s hospitals of Temple Street and Our Lady’s Children’s Hospital in Crumlin and also more specialised and our smaller regional hospitals like The Royal Hospital in Donnybrook and the Waterford Regional Hospital and many more. In 2010 the IHF produced the ‘Quality Standards for End of Life Care in Hospitals’ which acknowledged and offered guidance with the challenging issues of advance care planning (Irish Hospice Foundation, 2010).
In 2014 the Health Services Executive produced an update on the National Consent Policy (Health Service Executive, 2014a) highlighting in Part 1, Section 5.6 (Health Service Executive, 2014b) their guidelines for making decisions when the patient has lost capacity to consent to treatment. These guidelines refer to the patient’s best interests and to the patient’s values and preferences if known. In a study conducted in 2003, reported in the Irish Medical Journal (Butler et al., 2006), it was found that physicians in Ireland required greater national guidance regarding advanced care directives and in particular in regard to Do Not Attempt Resuscitation (DNAR) after 49% of the respondents expressed unsatisfactory understanding of issues relating to Irish DNAR orders.

The Irish Medical Council have developed their guides to assist doctors and patients alike to understand the standards of care expected of healthcare professionals. These guides have helped develop the important doctor-patient relationship that is based on ‘mutual respect, confidentiality, honesty, responsibility and accountability’ (Irish Medical Council, 2009). The Irish Medical Council reviews and updates its guides on a regular basis and the current guide to medical practitioners is now in its 7th edition with an 8th edition due to come out shortly.

There are a number of guides available to healthcare professionals and to the public listed below.

- Guide to Professional Conduct and Ethics for Registered Medical Practitioners from the Irish Medical Council (Irish Medical Council, 2009) – Section 41 (page 39) – Advanced healthcare planning, which covers advance refusals of treatment and/or a request for a specific procedure. It indicates that healthcare professionals are not obliged to provide treatment that is not clinically indicated.

- The Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives from An Bord Altranais (Nursing and Midwifery Board of Ireland, 2014) defines an advance healthcare
directive and outlines its principles for professional conduct. Its first principle is ‘respect for the dignity of the person’. Its standard of conduct indicate respecting and promoting the autonomy of patients, including decisions to refuse care or treatment which should be respected in the context of the person’s capacity. When a patient loses capacity the patient’s expressed view, wishes or directions if known, should be taken into account. The section ‘Supporting Guidance’ on page 14 covers advance healthcare directives.

- National Consent Policy 2014 (Health Service Executive, 2014a) – from the HSE. This policy indicates in section 7.8 on page 44 that an advance refusal of medical treatment is not legally enforceable but such advance healthcare plans should be respected when a) it was an informed choice, b) the stated decision covers the situation and c) there is no indication that the patient has changed their mind since the advance plan was made.

The proposed new medical legislation is finally catching up with the recommendations made by the Irish Law Reform Commission back in 2009 and the guidance already provided to healthcare professionals and patients alike.

1.1.2 Who wants advanced healthcare directives? And Why?
Advance healthcare directives are wanted by various groups

1. By patients themselves to protect their welfare and autonomy
2. By the substitute decision-makers to ease their burden of assisting healthcare professionals and making decisions for their loved one
3. By healthcare professionals to provide information on patient’s wishes and also to protect them from liability
4. By the Irish government to comply with international obligations and fulfil their duty to the citizens of Ireland.

Patients want them
Advance healthcare directives are not just for the sick and dying. It can be seen from some of the cases discussed previously, accidents or sudden catastrophic medical events may happen at any time or at any stage of life to anyone. It could be recommended that everyone should have an advanced care directive but specific groups could be initially targeted to introduce advance healthcare directives such as

1. All those 50+ years of age
2. Anyone with a significant medical diagnosis
3. After a recent move into a nursing home or supportive care environment

It is normally recommended to have a will to safeguard our wishes after we die. Now there is a ‘living will’, as they were called in the beginning in the US, which provides everyone with a mechanism to voice their wishes when they no longer have capacity to make these healthcare decisions for themselves or assign this decision-making authority on a trusted representative.

And just as in the case when one dies without a will, the courts may decide in how a person’s estate is passed on, when we do not have an advanced care directive which is valid and applicable, the medical team, the family and / or the courts may make these decisions on our behalf in our best interests. ‘Best interests’ would then be decided not by the patient but could be considered in the courts by someone who does not know the patient as a person. The courts would not know what the patient was like before they became incapacitated or what the patient wanted. In the case of AK (2001b), the courts decided to recognise the previously expressed wishes of the patient and allow in his ‘best interests’ for him to be allowed to refuse life sustaining treatment when he was close to death. However in the case of T (1992), the unconscious patient’s previous refusal of a blood transfusion was considered unduly influenced and it was in the patient’s best interest to preserve her life. Fenwick, in his article written in 1998, describes the source of ‘best interests’ in the treatment of incompetent or incapacitated patients as ‘to save their lives or to ensure improvement or prevent deterioration in the physical or mental health’ (Fenwick, 1998). However Fenwick goes on to highlight the change in opinion in PVS cases where decisions may also be
made by balancing benefits and burdens of treatments for the patient. In essence ‘best interests’ should be decided for the unconscious patient by reviewing as far as possible their present and past wishes and values which would have been likely to influence the patient’s decisions if they had capacity.

When making an advance healthcare directive an individual does not have to consult with a medical professional and may not be fully informed about the options of treatments that they are making decisions about. This may allow the patient to make autonomous decisions but it may leave the advance healthcare directive open to challenge if the patients decisions are deemed invalid or not applicable to the circumstances which arise in the future.

Most Irish people do want to have a say in how they are treated and especially in end–of-life care to provide for ‘dignity in death’ and quality of their dying (McCarthy et al., 2010). There are those however, who do not want to discuss or make decisions about their death and prefer to trust in the medical profession and family to make these decisions for them. This end-of-life or palliative care is so important and there is only get one chance to get it right for each patient (Irish Hospice Foundation, 2013) (Irish Hospice Foundation, 2012). It has a much better chance of being right for the patient, for their family and for the healthcare providers if they know that they are respecting the patients’ wishes, as stated in an advance healthcare directive.

Healthcare Professionals want them

Advance healthcare directives are widely advocated for end-of-life decisions but there needs to be increased training and understanding about advance directives and how they may be implemented. The main drivers of this implementation process for advance healthcare directives will be healthcare professions themselves. They carry the burden of decision-making at the moment but when their decision is in conflict with the patient’s family and friends, the advance directive can be a reference point for the preferences and wishes of the patient when they had capacity to decide for themselves. Due to the current legal uncertainty about making healthcare decisions for a
patient lacking capacity and where there is conflict between medical professionals and the patient’s family it may take going to court to resolve the issue. Of course going to court is a remedy of last resort and many healthcare facilities now promote clinical ethics committees to help mediate a resolution to such conflicts. Where a healthcare professional finds they have a conflict of conscience with regard to a patient’s request for treatment or even a refusal of treatment, like artificial nutrition and hydration, they would still be under an obligation of ‘duty of care’ to continue to care for the patient until another healthcare professional is found who is prepared to comply with the patient’s treatment decisions as articulated in an advance healthcare directive.

**Designated Healthcare Representative**
Being asked to make healthcare decisions for another person is a big responsibility. Doctors, trained and experienced, have to often make these decisions or at least guide a patient as to the best options available to the patient. A trusted friend or family member selected to be the designated healthcare representative may not have any of this medical training or any experience of dealing with end-of-life issues. This trusted friend is normally someone who knows you well and would understand what your wishes and preferences are. It is also someone who may be very distressed at your declining state of health or sudden incapacity. It is an advantage and support to them to have an advance healthcare directive which lays out the patient’s wishes and preferences to guide them at a time which is very emotional difficult for them. (Hickman and Pinto, 2014)

**Irish Government want Advance Healthcare Directives**
The new Irish legislation provides a framework to respect and comply with our international obligations. Patricia Rickard Clarke, a solicitor and former law reform commissioner, outlined these obligations in her presentation to the forum on the End of Life in 2014.(Irish Hospice Foundation, 2014a). They include the following:
1. **UN Convention on the Right of People with Disabilities.** This was signed in 2007 but may not be ratified until new legislation is enacted.

2. **Council of Europe - Legal Protections for Incapable Adults.**
   The State should respect the dignity of an individual as a human being.

3. **The Hagen Convention - International Protection of Adults.**
   The State should give recognition and enforcement of advance directives across national borders.

4. **European Convention on Human Rights.**
   This was incorporated into Irish law in 2003. It provides for a person’s right to self-determination and right to privacy.

5. **Convention on Human Rights and Biomedicine, 1997**
   Article 9 – previously expressed wishes. The previously expressed wishes relating to medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account.

6. **Universal Declaration on Bioethics and Human Rights**
   This provides for the recognition of human dignity, human rights and fundamental freedoms to be fully respected. Autonomy of the person to make decisions is to be fully respected. There should be special measures to protect those unable to exercise their autonomy.

7. **Council of Europe – Principles concerning powers of attorney in advance care directives – 2009**
   The right to determine an enduring power of attorney or make an advance healthcare directive supersedes a Ward of Court or a Public Guardian Regime.

8. **Council of Europe recommendation – Promotion of Human Rights of Older People – 2014**
   Older people should be respected for their inherent dignity. They have rights to regulate their affairs in the event they are unable to effect their instructions at a later stage.
1.1.3 Advance Healthcare Plans vs Advance Healthcare Directives

**Advanced Healthcare Plans** are prepared mainly by the medical healthcare team based on clinical information. Any decisions on medical treatment have to follow the HSE National Consent Policy (Health Service Executive, 2014a) and respect patient autonomy. Of course they must refer to the patient and their caregivers. The patient would be encouraged to discuss their condition and their wishes with family and friends for support and assistance. However some patients and their families may feel that information and discussion of the options has not been provided in an early and timely manner. (Lund et al., 2015) Some patients may find it very difficult to deal with discussions about death and dying and defer to the medical professionals looking after them. Even doctors may find it difficult to discuss end of life healthcare plans with their patients. They would try not to frighten their patients or may just have difficulty providing all the information around the decisions made in the healthcare plan in a clear and concise way that the patient would understand. These healthcare plans may be set up while the patient still has capacity and are used by the healthcare providers to guide courses of treatment like CPR, oral or IV treatments of antibiotics or whether comfort home care is more appropriate than attendance for acute care at hospital.

**Advanced Care Directives** are put in place by the persons themselves. Legal and medical advice is recommended but is not essential in preparing the advanced care directive. The advanced directive may ease some of the burden on the medical healthcare providers and the healthcare representative making decisions on behalf of the critically ill patient lacking capacity (Hickman and Pinto, 2014). Some medical healthcare professionals do have some difficulty with advanced care directives prepared without medical advice as they may be contrary to prescribed clinical practice. The instructions may be unclear or difficult to interpret for the healthcare professional. It is not even straightforward when a patient simply refuses a particular treatment. Under what conditions or situations does the patient not want a particular treatment? If a patient requests treatments is it clinically or
ethically appropriate to provide the treatment, drugs or therapy being requested? Are the resources available to comply with the request?

My answer then to ‘Why did Advance Healthcare Directives develop?’ is because patients want their autonomy and self-determination extended into the time when they no longer have capacity to give consent to or to refuse treatments. Patients want their wishes to be known and respected. They want their healthcare to be respectful of their human dignity. They may request certain care which adds to their comfort and quality of life and refuse other futile, often expensive, treatments which they may find burdensome or undignified at the end of life. They want to save their loved ones from making these difficult decisions at a time when they are possibly both vulnerable and emotionally distressed at the prospect of losing a loved and cherished friend or family member. Also it shall protect the healthcare professional from liability if they comply with a patient’s wishes in a legally binding refusal of treatment clearly stated in a valid advance healthcare directive.
Chapter 2

2.1 Ethical arguments concerning Advanced Healthcare Directives

2.1.1 Autonomy and Other Future Self
It has long been accepted that a patient’s autonomy should be respected. The four principles of biomedical ethics were introduced by Beauchamp and Childress in their book ‘Four Principles of Biomedical Ethics’ (Beauchamp and Childress, 2013), 1st Edition in 1978, and has become the most widely referenced framework of medical ethics. The four principles are:

1. Respect for Autonomy
2. Beneficence
3. Justice
4. Nonmaleficence

Autonomy means self-rule or self-governance and is defined by Beauchamp as ‘self-rule that is free from both controlling interference by others and limitations that prevent meaningful choice, such as inadequate understanding’ (Beauchamp and Childress, 2013).

Patient autonomy is centred on the patient’s capacity to give informed voluntary consent to treatment or to refuse treatment. Where capacity to make a decision is impaired there is a duty to maximise the capacity of the patient with ‘supported decision making’ to maintain respect for the patient’s autonomy.

No one can make a healthcare decision for another adult person unless they have specific legal authority to do so. For example where the patient is a ward of court (Health Service Executive, 2014b) or, under the proposed new legislation, where a designated healthcare representative is authorised by the patient in their advance healthcare directive. Patient autonomy can also be limited by the other principles like justice, where a request for treatment may depend on the availability of resources. Or, on the principle of nonmaleficence, where to comply with a request for a certain treatment which
may be of no benefit and clinically unsound and may actually harm the
patient, like requesting certain medication which the patient has heard might
be beneficial but the medical professional knows would do more harm than
good given the patient’s possibly complex health status. Also autonomy is
limited when by complying with the wishes of one person, it may cause harm
to others.
However the patient’s right to refuse treatment has been upheld in many
cases before the courts as referenced previously in Chapter 1.1. In a case
where the patient had capacity and was conscious,(1994) , the courts upheld
the patient’s right to refuse an amputation for a gangrenous leg. If an adult
with capacity refuses treatment this must be respected even if it may lead to
their death. The refusal may only be questioned if there is a lack of capacity
or the decision may impact or be harmful to a third person, for example a
pregnant woman, where an unborn baby may be at risk if treatment is
refused (1997b). These decisions by the patient are, up to now, about
making contemporaneous decisions based on information provided and
available at the time of the decision making.

So we can make decisions for our healthcare now, but can we make them
now for ourselves into the future? Degrazia (Degrazia, 1999) introduces this
concept of the ‘other person’, the ‘someone else problem’. How do we make
decisions for our future selves? Am I the same person who is now writing out
and signing an advanced directive as I will am in the future, in 10 years time?
As the advanced care directive should only be used if I have lost capacity in
the future to make these decisions for myself. I must be changed. At the very
least I am 10 years older and lacking capacity. But other things may have
changed too. My values may have changed, in 10 years time, older and
slower, I may place more importance on simpler things and family around me
than being able to do everything for myself. What I think of as unacceptable
now may be more tolerable with the passage of time. Myself, in the future is
‘another person’. Do I have the right to make decisions for another person? If
not me, who? Who else would be better suited to know what I would want? It
is a unique case of being allowed make a healthcare decision for ‘another me
– a different me in the future’. My future self does have a link to me now. She would have all the experiences and memories that I have now. This may not necessarily be the case if I am suffering from dementia, Alzheimer’s disease or even PVS, but there is still a physical, natural link that I am essentially identifiable with. My future self would have a link to me now plus the additional years in between. It is because of this potential to change my values and viewpoints over time that it is strongly recommended to review an advance healthcare directive regularly. There is no recommended time period to review your AHD but like an ordinary will you may consider reviewing it when –

1. As often as once a year like when I am getting an annual check up with my GP, when the options may be discussed with the GP.
2. My values may change, like a change to membership of a religion.
3. my circumstances may change, a serious illness has been diagnosed.
4. I am aging.

Even if there are no changes which I wish to make to your AHD it has been recommended by Patricia Rickard Clarke (National Council of the Forum on End of Life in Ireland) that I date each time I review the AHD to confirm that it stills reflects my up to date wishes and preferences. These regular reviews provide more certainty to my AHD and some protection from being challenged. Our new proposed legislation allows me not only to make decisions for myself in the future but also for me to give that legal authority to a designated healthcare representative to make decisions on my behalf in my best interests to cover the circumstances and situations which I am unable to foresee or provide explicit or exact instructions in my directive. This is not only allowing me to make decisions for ‘my future self’ but also allowing patient autonomy to be voluntarily passed on for the first time to a third person.

2.1.2 Personhood and Personal Identity Theory

I can made decisions for myself because I am a person, a human being, whose life is valued and whose self-determination is respected. But I can ask
questions like ‘when did I become a person?’, ‘when will I stop being a person’. The value of human life has been placed above that of other species of animal life. We are allowed to carry out research and testing on animals to provide treatments and drugs to help human beings but there are strict limitations on research on human beings. So when did I become a person? So was it at conception? But that is just a clump of cells with the potential to become a human being. Is it the foetus? Again it is really only a more developed clump of cells like many other animals at this stage of development. The baby, the infant, is that a person? We are getting closer to a person. Part of being a person is being unique. A person is unique by having unique DNA, fingerprints; even ear lobes have been identified as being unique to individuals. But what then about twins that have divided from the same embryo or that taboo area of science – cloning. Can we still be persons even when we are not unique? Our personal identity is unique and precious to each of us.

In the 17th Century, the philosopher, John Locke, attempted to answer the question ‘What is a person?’

*We must consider what a person stands for; which I think is a thinking intelligent being, that has reason and reflection, and can consider itself the same thinking thing, in different times and places; which it does only by that consciousness which is inseparable from thinking and seems to me essentials to it; it being impossible for anyone to perceive without perceiving that he does perceive.* (Locke, 1690)

So the definition Locke gives us concludes that a person should have the following properties:

1. Intelligence
2. Ability to think and reason
3. Capacity for reflection
4. Self consciousness
5. Memory
6. Foresight
So then back to the baby, it may have some of these properties but it is still only developing others like thinking and reasoning. But as we get into old age some of these properties may diminish with the effects of dementia and other diseases affecting our mental, physical and emotional wellbeing. Thus, even if we do not meet all of Locke’s criteria we are still considered persons and as such have a moral value. This connection to a moral value helps develop a principle of the value of human life. We cherish and protect it even or most especially when it is at its most vulnerable.

When we develop advance care directives, we are respecting the capacity of the human being to reflect on their future selves and make decisions that reflect their values. Especially in cases of persistent vegetative state where there are few signs of the person that was, the moral dilemma of turning off machines or withdrawing life-sustaining food and hydration is eased by the loss of most if not all of Locke’s criteria for personhood.

2.1.3 Capacity and Advance Healthcare Directives
At the centre of autonomy is capacity to consent. This is also true of advance directives. A person must have capacity to make the decision to prepare an advance directive for the time when he/she no longer has capacity to make these decisions. There is a general presumption of capacity for an adult over 18 years of age to make decisions about their own healthcare. If a person’s capacity is in question there is guidance to assist in assessing a patient’s capacity. (Irish Medical Council, 2009), (Health Service Executive, 2014b), (Nursing and Midwifery Board of Ireland, 2014)

Assessing capacity to prepare an advance healthcare directive follows the same guidelines as consenting to treatment

1. Ability to understand and retain information relevant to healthcare decision
2. Ability to apply the available information to their own circumstances and come to a decision
Making an advance healthcare directive also follows the standard guidelines that the person makes the directive voluntarily and is not under any undue influence or coercion.

After making an advance healthcare directive it only comes into force when the person loses capacity. Again there are general guidelines to assist in assessing the incapacity of a person. It may be temporary due to illness or medication or a more permanent decline and loss of capacity due to dementia or Alzheimer’s or other debilitating illness.

A person may be only having difficulty in making certain decisions at a particular time and should be assisted and provided with support in making independent decisions as far as possible. A person may be lacking capacity

1. ‘If a person is unable to understand, retain, use or weigh up information they have been given to make a relevant decision, or if they are unable to communicate their decision, they may be regarded as lacking the capacity to give consent to the proposed investigation or treatment.’ (Irish Medical Council, 2009)

2. If a person lacks capacity to make their own healthcare decisions reasonable steps should be taken to find out if they have an advanced care directive and contact their legal healthcare representative if they have one.

3. If no one else has legal authority to make decisions on the person’s behalf the patient’s doctor should
   a. Decide for the best clinical option
   b. Consider the patient’s past and present wishes if known
   c. Consider the views of people close to and familiar with the patient’s wishes, preferences and values.
   d. Consider the views of the other healthcare professionals involved in the patient’s care.

If the patient’s limited capacity is only temporary or if it may increase, time and assistance may be provided to the patient to make their own decisions when they have regained their capacity to do so.
So to have a valid advance healthcare directive I must have capacity to make the advance directive, I must understand what instructions I am giving and their consequences. For an advance healthcare directive to come into force I must have lost my capacity to make healthcare decisions for myself or by myself. I can give specific instructions concerning specific conditions, treatments I wish to have or treatments I wish to refuse. In our proposed new legislation I should be able to assign a trusted third person (a designated healthcare representative) to make decisions on my behalf to cover those circumstances which I have not been able to specify or foresee. The instructions in an advance healthcare directive should reflect my wishes and preferences and the values I cherish. These values can be formed and influenced by many factors from family, community and even religious beliefs.

2.1.4 Cultural influences and advances in medical treatments

My values can be strongly influenced by the culture I grew up in. In the past in Ireland families traditionally looked after their elderly relatives at home. People expected and trusted doctors to know what was best and provide all the healthcare support they needed. Now with medical advances people are living longer. Patients in intensive care units (ICU) can survive serious illness and catastrophic injuries but can be left alive living with prolonged chronic or critical care needs. The doctors can even keep the body alive for some time in a persistent vegetative state. So now the question arises for the patient about how much healthcare does she/he want?

Patients may request all measures to be taken to prolong life. However this may be limited. It may depend on the ethical principle of justice in the management of healthcare resources. Or it may not be clinically indicated and the healthcare professionals deem it inappropriate to provide the requested treatment. These are some of the reasons requests for treatments are not legally binding.

Patients can also refuse treatments when they place an unacceptable burden on them, when their quality of life is diminished or the treatment may be
considered futile. This may mean that patients, who are terminally ill, old and fragile, possibly suffering from dementia, refuse to go to hospital repeatedly for assistance with illnesses like aspiration pneumonia. Or they may wish to refuse CPR as the risks of breaking bones and injury are very high compared to the possibility of recovery, which has been found to be rarely effective for elderly patients (Murphy et al., 1989) (Guidance from the British Medical Association et al., 2014).

Their simple wish to die at home, requesting care and assistance from community healthcare resources, even palliative nursing, may not only be respecting the patients’ wishes and allowing them to die with dignity at home, but in general these forms of less invasive procedures and healthcare supports, which are more likely to fulfil the patient’s wishes, are also less expensive than the hospital care that a dying patient no longer wants.

There have been great improvements and advances in medical healthcare all over the world. Old and young alike are now successfully treated in Intensive Care Units (ICUs) in ever greater numbers. In the USA, Sjoding and Cooke (Sjoding and Cooke, 2015) comment on the improvements and increasing success of survival in ICU for even the most severely ill and injured patients. However, this ICU success in saving lives brings an increasing burden on the healthcare system looking after the increasing number of chronic critically ill patients who survive their initial acute illness. 67% of patients who recovered from ICU care are discharged to long-term chronic care in hospitals or other chronic care facilities.

The current European population is just over 728,000 people and the estimates are that in Europe the population will actually decrease to approx 653,000 by 2050. There is an estimated decrease in age groups 0-14 and 15-64 but there is an increase of over 55% in the age group 65+. Here in Europe this means that about two people of working age will be needed to support one retiree. The Irish Longitudinal Study on Ageing (TILDA) adds substantially to the scientific knowledge about ageing in Ireland (Kenny and Barrett, 2010). This study outlines some key features of the ageing-related
issues and the large increase in the older populations confronting many countries in the world including Ireland. The percentage of the population in Ireland over 65 years is projected to be 14.1% by 2021 and as much as 22.4% by 2041. In general, healthcare needs increase with advancing age. A better understanding of types and frequency of diseases and disabilities is essential for policy planning and provision of a quality healthcare system. The link between an ageing population and healthcare spending is complex, but it is influenced by the fact that people are living longer and there is an overall improvement in the quality of older people’s health. Higher spending is projected for long term care and healthcare spending is mostly concentrated into the last year of life. For example, one UK study found that while people in their last year of life made up only 1% of the population, they accounted for 29% of hospital expenditure (Seshamani and Gray, 2004). The number of deaths in Ireland from dementia has risen steadily, 51.3% increase, from 2007 to 2011 (Kane et al., 2015).

![Causes of deaths in Ireland in 2012](image)

Fig 2.1.3.1 Causes of deaths in Ireland in 2012 (Irish Hospice Foundation, 2013)

Dementia patients as well as cancer patients have the possibility now due to earlier diagnosis of being involved at a much earlier stage in their advance healthcare planning (O'Shea, 2007). The challenge is to promote patient rights and advocacy to be at the centre of decision making for people with
dementia, allowing them to play a central role in the planning and delivery of their own care. Dementia is now considered as one of the many conditions to have palliative care needs. Providing appropriate support for increasing numbers of patients with neurodegenerative diseases like dementia in a country with one of the fastest aging demographics in Europe presents a significant challenge to palliative care services in Ireland. Specialist palliative care has been shown to decrease hospital admissions in the last year of life and increase the odds of home death and has been shown to improve symptoms and quality of life for patients (Kane et al., 2015).

On the positive side the data suggests that ‘Ireland’s older adults experience a high quality of life’ and are as a group generally involved in the community-based care to spouses, friends and neighbours. Further studies are planned for institutional based long-term care in nursing homes which will inform new models for developing health and social care delivery.

More people need to prepare advance healthcare directives stipulating their wishes for appropriate care for their needs. In 2010, 74% of Irish adults expressed a preference to die at home however only 26% were able to do so. (McCarthy et al., 2010, Irish Hospice Foundation, 2014c)

![Place of death in Ireland in 2012](image)

**Fig 2.1.3.2** Place of death in Ireland in 2012 (Irish Hospice Foundation, 2012)
In 2004 only 14% of the Irish population stated they had written an advanced directive or living will (Irish Hospice Foundation, 2004). More alarming is the lack of awareness of terminology around end-of-life with 71% of Irish adults indicating they had never heard of ‘advance directives’. A third, 31%, had never heard of a ‘living will’. The overall findings of the survey found highest awareness of end-of-life terminology was amongst middle-class, <65, female, with higher levels of education. So considering that the awareness of advance directives is so low it is not surprising that so few have actually completed one. Education and information to the general public is imperative to improve understanding of the benefits of an advance healthcare directive in patient care, from expressing your wishes to be treated with dignity, to not being resuscitated if it is the patient’s wish. Advance directives may also reduce the costs to the healthcare system by reducing the futile frequently very costly healthcare given to the patient.

2.1.5 Medical advice and medical treatments
Healthcare professionals take an oath to ‘first do no harm’. It can be difficult to comply with a patient’s directive to refuse treatment when the medical advice would be to continue with treatment because the odds are good for a recovery but the patient’s abilities to do certain activities which they find very important in their lives would be limited. This question of ‘quality of life’ over life itself is so important and personal that the decision should be left with the person living it. One person may feel that living with a severe disability or illness makes life not worth living while another person relishes every moment of life whatever the ‘quality’ of that life is (Guyatt et al., 1993). This must also be balanced with the ethical principle of the sanctity of all life and making decisions that favour the preservation of life. Sanctity of life is the traditional value that all life is sacred and we should never intentionally end a human life (Kuhse, 2002).

Even though the statistics say I will be living for longer does that mean that I will be living a healthier life, or more tolerable with the impacts of old age which affect mobility and make us more fragile? With all the changes to our
life styles, am I really healthier? There are issues which affect our health and healthcare now more than ever before and which are more directly associated with life style. Estimates of the numbers of chronic health conditions from 2010 to 2020 are increasing like diabetes (a rise of 30%), chronic heart disease (a rise of 31%) and obstructive pulmonary disease (a rise of 23%). Three in four people in Ireland over fifty are either overweight or obese. One in every two smokers will die of a tobacco-related disease. Mental illness is a growing health, social and economic issue with an Irish mortality rate from suicide in the 15-24 age groups, at 14.4 per 100,000, which is the fourth highest in the European Union (Health Service Executive, 2009). Our historically high alcohol consumption is not only responsible for many cancers and heart diseases but is also a contributory factor in half of all suicides (Health Service Executive, 2013).

Due to improvements in healthcare there are now many more options to help control the symptoms of these illnesses and maybe even in the future to cure them. Some of the improvements in healthcare such as the use of penicillin and other antibiotics have been so overused that now they are no longer as effective as they once were (Mainous et al., 2000). Also there are an increasing number of new strains of antibiotic resistant organisms being identified (Littmann et al., 2015). I may be living longer but I may also be at risk of living with more chronic diseases than ever before. Advance healthcare planning may, with the participation of the patient, limit the amount of active treatments for these chronic diseases, which may become over burdensome, and opt instead for comfort care or palliative care to assist with optimising quality of life and minimising pain and discomfort. These decisions for comfort care or even refusal of treatments can pertain to the time when the patient loses capacity. This was shown to be the case in AK (Medical Treatment: Consent) (2001b) where a 19 year old patient with motor neurone disease knew and understood the inevitable progress of his disease and directed that his ventilator should be turned off two weeks after he lost his ability to communicate his wishes.
In conclusion the ethical arguments favour advance healthcare directives as a means of protecting and promoting patient autonomy even if it means refusing life-sustaining treatments in favour of quality of life and comfort care. However there are limitations, if a refusal of treatment may adversely affect another person. This is self-evident in the case of a pregnant woman, but it may be as simple as a burden of care on healthcare providers, carers, family and friends, if time and resources are required for patient care. Requests for treatment may similarly affect a burden on resources to comply with the individual’s request in a healthcare system which is trying to meet ever increasing demands on its resources.

In promoting advance healthcare directives it is essential to provide adequate education and information in a simple easily accessible manner. All stakeholders need to understand what is being stated in an advance healthcare directive so unintended outcomes do not occur. The validation of transferring patient autonomy to a designated healthcare representative, selected by the individual, is further respecting and supporting patient rights in having a say in their own healthcare decisions.

However advance care directives not only have the potential for doing good there is also the potential for doing harm. Not understanding the implications of the decisions made in an advance directive may lead to conflicts within families or between families and healthcare professionals. Not updating an advance care directive may mean that it no longer reflects your current values. Having an advance care directive which does reflect your values and preferences does not always means that it is available to the healthcare professionals or carers reacting to a particular emergency. Making decisions in an advanced care directive without medical advice may leave them open to challenge from clinical staff who will counter that they are acting in the patient’s best interest. Making decisions in the advance care directive which are no longer current or up to date with clinical practice or medical technologies also leave them invalid or inapplicable to the particular medical emergency. It is simply not possible to foresee all possible situations which may need a decision about end of life care. Indeed many may leave making
an advance care directive until it is too late and their capacity to make one is in question.
Chapter 3

3.1 How are the laws being interpreted?

3.1.1 Advance Healthcare Directives vs Enduring Power of Attorney

Enduring power of attorney has been available to Irish citizens since 1996 under the Enduring Powers of Attorney Regulations 1996. (1996a). It is a legal instrument which enables a ‘donor’, the individual giving the power, to choose a person, ‘attorney’, to manage their property and affairs in the event of becoming mentally incapable of doing so themselves. It may also deal with issues relating to personal care decisions, such as

a) Where a person lives; at home or in a nursing home.

b) With whom the donor lives

c) Who may or may not be allowed to visit with the donor

d) What training or rehabilitation is provided to the donor

e) The donor’s diet and dress

f) Inspection of the donor’s personal papers

g) Housing, social welfare and any other benefits which the donor would be entitled to.

These personal care decisions should be made with due consideration of the donor’s best interests and their past or present wishes and preferences.

It must be

1. Witnessed by both the donor and the attorneys (there may be more than one attorney)

2. Notice of the EPA is provided to at least 2 other close family members.

It may deal with all the donors’ property and affairs or be limited in scope by the donor. For example the attorney may not be allowed to sell the family home.

Notice is given to the donor and the notice parties of the registration of the enduring power of attorney who may at that stage make any objections. Once registered it cannot be revoked unless the Court agrees. The power
only becomes effective when the donor is incapacitated. The application for the enduring power of attorney includes

1. a statement by a registered medical practitioner to confirm that the donor had capacity to understand the effect of creating the power.
2. A statement by the solicitor preparing the legal instrument that they believe that the donor is not acting as a result of fraud or undue pressure.

An enduring power of attorney does not cover healthcare decisions involving consent to or refusal of clinical treatment. An advance directive under the proposed new legislation will be the only legal mechanism in Ireland to provide for advance healthcare decisions.

**An Advance Healthcare Directive** in contrast may be prepared without consultation or statements from a medical practitioner or solicitor. It is however strongly recommended to consult with both your GP and solicitor when writing up an advance healthcare directive. As the name implies it covers all forms of care decisions from healthcare treatment decisions to welfare decisions on where a person lives. It may cover

1. Treatment requests
   a. May depend on available resources to comply with request
   b. These are not legally binding
   c. Consideration is given to stated preferences when possible
   d. It cannot be illegal eg euthanasia
2. Treatment refusals
   a. Normally these have legal standing
   b. May include refusal of life sustaining treatments
   c. May not include refusal of basic care, warmth, comfort and oral nutrition and hydration.

The advance healthcare directive should be in writing and should be witnessed by two adults, one of whom is not entitled to inherit from the person writing the directive.
The advance healthcare directive gives some legal certainty about future care. However for it to be valid and applicable it needs to be very specific and carefully worded.

The advanced care directive can be amended or revoked verbally or in writing only up to the point when the author becomes incapacitated.

Of course for the advance healthcare directive to be effective it must be available to the healthcare professionals involved in the patient's care and also clear and concise in its instructions. The instructions must be intelligible so that they can be carried out by the healthcare staff.

To prepare an advance healthcare directive I can if I wish prepare it without medical or legal assistance. It must however be specific to the healthcare decision to which I want it to apply. For example, I am old and frail and do not wish to have CPR in the event I have a cardiac arrest. This may be indicated to my carers, GP, hospital carers or even nursing home carers, so that my wishes are known and respected. I may select a trusted friend to make healthcare decisions on my behalf for situations I am unable to foresee or specify. The advance healthcare directive can cover healthcare as well as welfare decisions.

I must have capacity to make either an EPA or an advance directive and I must lose capacity for either to come into force.

The formality of the EPA makes it more difficult and costly to set up but then its implementation is more easily enforced and the attorneys making decisions are fully informed in advance. It has extra safeguards, like the notice parties, to protect against unwise or even fraudulent decisions by the attorneys. The advance directive is much easier to set up but if lacking very clear, valid and applicable instructions its implementation can be fraught with difficulties. Not least of which is making sure that the healthcare providers making clinical decisions are informed of the advance directive and the
patient’s instructions. There are no safeguards to assess that the patient was not coerced into preparing the advance directive or that the designated healthcare representative is making decisions that reflect the patients preferences and not their own.

3.1.2 What’s happening in the US?

After the California Natural Death Act in 1976 (1976b) ten more U.S. states passed natural death laws. They allowed patients to set up ‘living wills’ where they were able to set out their preferences with regard to life-sustaining medical treatment. Living wills is the term used frequently in the U.S. where we use advance directive or advance healthcare directive or just advance care directive.

In 1985 the US Uniform Law Commissioners proposed the ‘Uniform Rights of the Terminally ill Act’ (1989). This was amended in 1989. However the Uniform Law Commissioners recognised that this legislation was limited in considering only patients suffering from a terminal illness.

‘The scope of the Act is narrow. Its impact is limited to treatment that is merely life-prolonging, and to patients whose terminal condition is incurable and irreversible, whose death will soon occur, and who are unable to participate in treatment decisions.’

The Patient Self-Determination Act in 1990 (1990b) tries to address the problem of educating both patients and healthcare professionals about advance healthcare directives. It requires all federally funded healthcare institutions to inform patients of their right to refuse life-sustaining treatment and assist them in completing an advance directive and recording it on their medical record. The Act covers not only the recording of the patient’s preferences for medical treatments but also includes

1. The appointment of an agent or surrogate to make health care decisions on behalf of such an individual
2. Instructions for the disposition of organs.
By 2000 ‘living wills’ were accepted in all 50 American States. They were supported by doctors, lawyers, non-profit groups and even the American Medical Association. Despite all this support, a 1991 Gallup Poll found, 75% of Americans supported living wills while only approx 20% of them had one, these were mostly elderly people. In 2004, Morrison and Meier carried out a survey of 34 randomly selected elderly care centres in New York and found that over 33% of the participants had completed a Living Will (Morrison and Meier, 2004). A more recent survey in 2010 indicated that there are 25% of Americans with Living wills (Novotney, 2010). Some barriers were identified to making a living will (Kumar, 2000). People assumed they were ‘costly, full of legal jargon and involved hiring a lawyer’. Also ‘no one wanted to talk about death and dying’. In actual fact living wills are simple to set up and do not require a lawyer, you only need two witnesses to sign it. In planning and deciding on what you want in a living will it is also very important to take the time to talk to loved ones about your decisions. If you do not communicate the fact that you have an advance directive with your doctor and family you will have problems having your wishes, which you have made the effort and taken the time to write down, respected and implemented by your healthcare providers. Anita Kumar in her article in the St. Petersburg Times, Tampa Bay, says that according to the Regional Ethics Network of Eastern Washington and North Idaho half of the doctors across America don’t know that their patients have made an advance directive or living will, because their patients haven’t told them or the doctors haven’t asked (Kumar, 2000). Talking is just as important as filling in the document. Not just talking to your physician but also your family and friends. It helps everyone understand your reasons for your decisions and how a caregiver can help implement your wishes. Without this discussion living wills may not be implemented the way the author wanted. Kumar also states that according to the National Right to Life Committee, (National Right To Life Committee, 1992), one in four doctors do not abide by living wills. This could possibly be due to lack of communication but also perhaps because they are not applicable to the situation or not understandable to the attending doctors looking after the patient’s care.
There are those who support and assist patients in preparing a living will, like Aging with Dignity with their popular document called ‘Five Wishes’ (1997a). They assist with

1. Who you want to make health care decisions for you when you can’t make them
2. The kind of medical treatment you want or don’t want
3. How comfortable you want to be
4. How you want people to treat you
5. What you want your loved ones to know

This has become widely popular with over 23 million copies in circulation across the states. Five Wishes meets the legal requirements in 42 states and is useful in all 50 states. It is probably because it is written in everyday language and provides a simple straightforward structure to start conversations about care in times of serious illness that it has become America’s most popular living will. It has become available online since 2011, as well as in print format, in 28 languages. The project was initially supported by a grant from the Robert Wood Johnson Foundation but is now funded by a small charge of $5 per print copy or $5 per use online. The charge is further reduced when ordering multiple copies which makes it easily accessible to groups or institutions like nursing homes.

There was another type of advance directive created in 1992 by the National Right to Life Committee. Their version of a living will was called a ‘Will to Live’ (National Right To Life Committee, 1992). This asks for medical treatment and does not refuse life-sustaining treatments. The Will to Live is a presumption for life and wants to protect against courts making decisions to withdraw ANH to allow a patent to die where their quality of life is no longer deemed worthwhile. A ‘Will to Live’ makes it very clear that the patient wants ANH and other life-sustaining treatments. The National Right to Life Committee would have been arguing for the preservation of life in the Terri Schiavo case, where it was unknown what Terri would have chosen for herself, and wish to guard against the possibility of euthanasia where ‘quality of life’ is put before preservation and sanctity of life.
More recently, in 2009, Levi and Green from Penn State College of Medicine have introduced a computer-based decision aid which tries to address some of the concerns and criticisms against advance directives (Green and Levi, 2009). The website is https://www.makingyourwishesknown.com/ and it does this by

1. Educating users about advance healthcare planning
2. Helping individuals identify, clarify, and prioritize factors that influence their decision-making about future medical conditions
3. Explaining common end-of-life medical conditions and life-sustaining treatment
4. Helping users articulate a coherent set of wishes with regard to advance healthcare planning, in the form of an advance directive readily understood by physicians
5. Helping individuals both choose a spokesperson, and prepare to engage with family, friends and healthcare providers in discussions about their advance healthcare directive and their wishes for their future healthcare.

Having reviewed the website and prepared up an advance healthcare directive using it, I found it user-friendly, simple, straightforward, quick and easy to use. It provided very useful information and educational expert advice on various aspects as you proceed through the steps in preparing the advance directive. It offered not only an option to allocate surrogate decision making authority on one trusted friend but two additional alternatives if anything happened to either of the initial two selected decision-makers. Also to support the decision-makers there was an additional option to recommend expert support to the decision-maker to aid them in making decisions on behalf of the patient. The print out of the advance healthcare directive then allowed me to review it and discuss it with family members. This step in the process of preparing an advance directive is very important and allowed for discussion and possible amendments to clarify the advance healthcare directive. It was freely available to use on the internet website in accordance with the terms of use. It is not a substitute for getting medical or legal advice.
and advises users to seek expert assistance if required. The information on the website is not guaranteed to be accurate, complete or current as changes may occur rapidly in the medical or legal fields and again it advises the user to verify the accuracy of the information presented on its website. See Examples of the website and web pages, including an example PDF of an advance care directive in the Appendix of this dissertation.

Despite all the aids and promotion of advance directives it has been found that approx 25% of adults in US (Novotney, 2010) have executed an advance directive. In the event you are suddenly ill and accessing acute care only 26% of patients with an advance directive have their directives recognised while in hospital. However it does appear that where the advance directive is recognised in 86% of cases the advance direct influenced treatment decisions. (Morrison et al., 1995) This article written by Morrison in 1995 showed the need to overcome the barriers to easily and quickly access the patient’s advance healthcare directive. An example where an advance care directive would be very helpful in the care of patient arriving at A&E is where the patient has a head trauma or is suffering from dementia and can no longer remember important information about themselves or their normal healthcare status. The advance healthcare directive may state not only the important ‘in case of emergency’ information like medications and allergies, but also the DNR status or other treatment options already decided by the patient.

In 1996, Dr. Joseph Barmakien set up the U.S. Living Will Registry (Barmakian, 1996) in response to the problems of finding and accessing the current version of a patient’s advance directive. Each time a patient would be admitted into hospital the hospitals were legally obliged to ask the patient if they had an advance directive and store it on their medical file. Healthcare providers had various problems in storing and retrieving the advance directive. It took time to search and verify that they had the correct most up-to-date version. The website provides access to the patient’s advance directive by simply entering
1. Source (or hospital where the patient first processed the registration of the advance directive) and
2. Registrant’s ID Number (which the patient would keep on a wallet card provided to him at registration)

‘The mission of the U.S. Living Will Registry is to promote the use of advance directives through educational programs, and to make people’s health care choices available to their caregivers and families whenever and wherever they are needed, while maintaining the confidentiality of their information and documents.’

This registry electronically stores advance directives, organ donor information and emergency contact information, and makes them available across the USA 24 hours a day to all healthcare providers. It is an independent service to provide access to a patient’s most up-to-date version of their advance directive.

Even the level of physician awareness of advance directives can sometimes be lower than desired. In a survey of Hospitals in Texas in 2007 only 81% of respondents were aware of all the provisions of the Texas Advance Directives Act. A minority of hospitals actually used the procedures to comply with the Act and most cases were solved before the end of the mandated 10 day waiting period because

1. Patients died
2. Patients or representatives agreed to forgo the treatment in question
3. Or patients were transferred

It was rare that life-sustaining treatment was discontinued against patients’ or patient representative’s wishes. (Smith et al., 2007)

In the US where advance directives were first legalised nearly 40 years ago there is still some difficulty getting information out to the public about advance healthcare directives, and the value of creating one. Even the medical profession are not fully aware or competent in implementing the procedures to recognise and follow patient’s advance directives.
The US authorities want to only recommend seeking medical advice, not to make it a formal requirement. They considered a requirement for more formality was ‘inappropriate and unduly intrusive’ for the current competent person preparing the advance directive. (Maclean, 2008) However the future incompetent self would be very vulnerable to having the advance directive deemed invalid or not applicable if the details in the advance directive were not intelligible or specific in medical terms with regard to the decisions needed. Making medical advice a requirement in preparing an advance directive may be justified by the enhanced security in the implementation of a fundamental life choice.

In Virginia they have also introduced an additional power to their advance directives. It is called a ‘Ulysses Clause’ and is applicable where a patient makes an advance directive for the situation when they may have a relapse in their condition eg schizophrenia and refuse treatment which they would not refuse if they were well. The name ‘Ulysses Clause’ was so named after the pact that Ulysses made with his men. He wanted to listen to the song of the Sirens, who would lure him into the water, and his death. His men had wax put into their ears so that they would be protected from the influence of the Siren’s song. Ulysses was tied to the mast and his men were ordered to ignore any orders he made while under the influence of the Sirens, whose song would drive him temporarily insane. So in this case the written advance directive would authorise treatment over the objections of the incapacitated patient. This may also be extended to the authority of the designated attorney to make these treatment decisions over the objections of the incapacitated patient.

In Ireland this provision was included in the ‘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’(Centre for Disability Law & Policy, 2014), where following the UN Convention on the Rights of Persons with Disabilities it allowed for the insertion of a ‘Ulysses Clause’. It must be specifically stated in the directive that the individual’s
written preference would take precedence over verbal objections only under certain conditions and specified periods and is subject to independent execution safeguards.

3.1.3 Can we look to UK for guidance?

The UK was similarly affected by a number of legal cases before the courts which promoted legislation to cover advance directives. Prior to any laws covering advance directives there was the high-profile Bland case

1. Airedale NHS Trust v Bland 1993 (1993a)
   Anthony Bland was severely injured in the 1989 Hillsborough football stadium disaster. His injuries caused him to be left in a persistent vegetative state (PVS). An application was made by the medical team looking after Anthony that, while there was no hope of any recovery, the court would approve a withdrawal of artificial nutrition and hydration (ANH) and only continue treatment which would allow him to die peacefully and with the greatest dignity possible. The Court agreed. In their summing up Lord Keith and Lord Goff referred to patient’s autonomy in refusing life-sustaining treatments and the possibility of giving such an instruction in advance of incapacity.

Following on after Bland the following cases dealing with a patient’s capacity to consent to treatment or refuse life-sustaining treatment were judged and upheld in the English courts.

1. Re C (Adult: refusal of treatment) 1994 WLR 290 (1994)– A patient at a secure hospital was refusing an amputation. He was a paranoid schizophrenic but the judge found that ‘a person may have capacity to manage his affairs not withstanding that he has schizophrenia’ and was thus competent to refuse treatment now and in the future. It was the first English case to enforce a patient’s
refusal of treatment. It was important to illustrate the patient’s capacity to refuse treatment which was not only about end-of-life but also about continuation of care.

2. Re AK (Medical Treatment: Consent) 2001 (2001b)– the case involves a young 19 year old suffering from Motor Neurone Disease (MND). Using blinking eye movements AK requested that two weeks after he lost his ability to communicate he wanted the ventilator to be removed. The patient’s advance directive was upheld to refuse treatment and the ventilator was removed. The problem in this case may be argued that it was difficult to assess the patient’s competence due to the limited and difficult means of communication.

The two cases above are the only cases in the UK where a patient’s capacity to refuse treatments was upheld and the patient’s refusal of life sustaining treatment was respected. There is also the view that the advance directives were upheld due to very poor quality of life for the patient. (Maclean, 2008)

The following cases illustrate where an advance directive was not upheld

   This case concerns a pregnant woman who was involved in a motor accident. She signed a form of refusal for blood transfusions allegedly under the influence of her mother who was a practising Jehovah’s Witness. After the still birth of her baby her condition deteriorated and she needed life-saving blood transfusions. Her father and boyfriend sought judicial authorisation for the administration of the blood products and blood transfusions which were needed to save her life. The Court found that the patient’s refusals were invalid because of incapacity and that treatment was in her best interests. Lord Donaldson found ‘a special problem arises if at the time the decision is made the patient has been subjected to the influence of some third party.’ Patient’s decisions should be a
a. Clearly established choice – voluntary and without undue influence
b. Applicable in the circumstances – appropriate care for the given circumstance and whether it was covered under the directive.

2. HE v A Hospital NHS Trust (2003) (2003a) The case concerns a 24 year old Jehovah’s Witness who was born a Muslim. She needed a life-saving blood transfusion. She was in septic shock, had been sedated and was unconscious. She had lost capacity to consent to treatment. She had signed an advance directive refusing blood transfusion under any circumstance. However she had recently changed back to Islam and was engaged to a Muslim man. She had not attended any Jehovah’s Witness meetings in some time. In the Court’s judgement it was found that there was considerable doubt if the advance directive was still valid and applicable as she appeared to have had a change in her values in renouncing Jehovah’s Witness. These very real and valid doubts put forward by the patient’s father must be resolved in favour of preservation of life. This was despite the fact that the advance directive was made only 2 years previously and the patient had not revoked it. Again we can see from this case the importance of keeping the advance directive up-to-date reflecting any changes of your values.

3. W Healthcare NHS Trust v H (2005) (2005b). Here a 59 year old woman with Multiple Sclerosis had 10 years previously discussed with her daughter that she didn’t want to be kept alive by machines and with a close friend that she didn’t want to be a burden to her daughters or kept alive if she no longer recognised them. It was judged that the verbal discussions of advance wishes were not sufficiently clear to refuse ANH. So the ANH should continue as she may not have understood the consequences of death by starvation. The advance directive was open however to the
possibility of covering refusal of treatment for infections or life support machines.

Following on from these cases the Law Commission for England and Wales proposed that ‘advance refusal of treatments’ should have legal standing. Their recommendations were implemented in the Mental Capacity Act 2005 (UK Government, 2005) which covers the recognition and validity of advance directives in Part 1 Sections 24-26. It allows for the informal verbal advance directives to be recognised when refusing treatment in general circumstances. However in Section 15 Subsection 5 & 6, if the advance directive is a refusal of life sustaining treatment the advance directive must

1. Indicate that the patient understands the risk to life
2. It is in writing
3. Signed by the patient
4. Witnessed in patient’s presence

This formal drafting in writing of an advance directive and witnessed by a third party allows an opportunity to check if the person is fully informed of the consequences of their instructions, especially if refusing life-sustaining treatments, whether the person has capacity and is not under any undue influence.

Withdrawals, even partial withdrawals, or alterations which do not involve life-sustaining treatments can be made simply by telling someone about your change of mind.

The Mental Capacity Act 2005 stipulates in section 24 that the ‘advanced decision’ must refer to ‘a specified treatment’. So as was seen in W Healthcare NHS Trust v H (2005), H may have refused artificial ventilation, ‘a machine’, it did not cover the medical procedure of ANH. A Jehovah’s Witness may specify a refusal of blood transfusion but if there is a perceived change of mind this may also be deemed invalid, HE v A Hospital NHS Trust (2003). It is still unclear if a general expression like ‘life-sustaining treatment’ counts as a ‘specified treatment’. So how do I make a valid and applicable advanced care directive? If the directive is not very carefully phrased instructions in the directive may be deemed invalid or not applicable. If there
is a perceived change of mind the directive may be challenged and may be
demed invalid. Also if the specific treatments listed in the directive do not
cover the current situation the directive will not be applied.

Where the initial understanding that an advance healthcare directive could
only be revoked or amended by the author when the author had capacity to
do so, the Act has introduced some leeway to this understanding. In Section
24 (3), it is very clear that ‘P may withdraw or alter an advance decision at
any time when he has capacity to so’, but in Section 25 (2 c) an advanced
decision is not valid if ‘P has done anything else clearly inconsistent with the
advance decision remaining his fixed decision’. This was highlighted in HE v
A Hospital NHS Trust (2003). In this case the patient had demonstrated a
change of mind or value before losing capacity but it is also possible to
interpret Section 25 (2 c) to cover actions made by the patient after losing
capacity. For example in a case where the patient had made a refusal of
treatment decision if he no longer recognised family or friends due to
advanced dementia. However, when the patient had lost capacity, was in a
state of advanced dementia, but seemed content with his day to day care
and his quality of life; his contentment may be enough to invalidate his
advance healthcare directive. The 2005 Act is accompanied by a Code of
Practice which also follows the recommendations of the Law
Commission.(Lord Chancellor, 2007)

In Scotland there is no case law concerning advance directives there is one
case in 1996 where the Court of Session with the Lord Advocate (Scotland’s
Chief Criminal Law Officer) decided that it was lawful to withdraw nasogastric
feeding from Mrs Janet Johnston who had been in a persistent vegetative
state (PVS) for four years after a drug overdose (McLean, 1996). Her
relatives had asked her doctors to remove the feeding tubes and allow her to
die. Unlike the earlier Bland case in England which had been heard as a civil
case the Johnstone case was under the criminal jurisdiction of the Lord
Advocate. Scotland’s senior Civil Judge, Lord Hope, (The Lord President) set
out a framework within which such decisions could be taken. He stated that
there is no legal obligation on a doctor to continue treatment which is futile or has no medical benefit to the patient and is not in the patient’s best interests. Lord Hope tried to define the ‘best interest’ of the patient as when treatment would provide no benefit for the patient. The Lord Advocate went on to issue a policy statement to the effect that he would offer immunity from prosecution to every doctor who disconnected the nasogastric feeding from any patient in PVS where the Court of Session had authorised this. So doctors in Scotland have both a framework from the Lord President and immunity from prosecution from the Lord Advocate. However, this application of ‘best interest’ of patients remains a difficult test when applying it to PVS patients. As when can it be in the ‘best interest’ of a person to starve to death? (Fenwick, 1998) It can be better understood in an assessment of benefits against burdens and in the Bland and Johnstone cases the ‘net benefit’ outweigh the burden of continued existence in a vegetative state with no prospect of recovery.

The Scottish Law Commission had included a provision for advance statements in their original draft for legislation to the Scottish Executive in 1995 (Scottish Law Commission, 1995). This was specifically excluded by the Scottish Executive when drafting the new statute in 2000, Adults with Incapacity (Scotland) Act 2000 (2000) when they stated ‘attempts to legislate in this area will not adequately cover all situations which might arise, and could produce unintended and undesirable results in individual cases’. They felt that ‘such proposals did not command general support’. In a position statement from the Scottish Council on Human Bioethics in 2006 (Scottish Council on Human BioEthics, 2006) they outlined 5 points dealing with advance directives:

1. Advance directives may be considered even though they are not legally binding.
The Council had concerns about the validity of the directive, the establishment of capacity at the time of making the directive, the possibility of revoking the directives and making that revocation known or whether the directive is applicable to the medical situation.
2. Advance directives should not be used to address quality of life matters.
   Despite patient concerns about degrading and drawn out treatments where there is poor quality of life there is a balance to be found for quality of care and rehabilitation which may enable patients to live the lives they value.

3. Legally binding advance directives may impose unworkable obligations upon medical professionals.
   This is an obvious reference to requests for treatment which would be against medical advice. It may prevent providing appropriate care that is in the patient’s best interest.

4. Legally binding advance directives may be abused.
   Patients may be coerced or unduly influenced into an advance directive which would not be in their best interest. It may even open the door to illegal services e.g. euthanasia, where a refusal of basic care could lead to or hasten death.

5. Advance directives may be misinterpreted
   Without any reference to medical or legal advice an advance directive may not make sense to the healthcare provider. It may lead to confusion and outcomes which were not the intention of the patient.

So in Scotland they have not made advance healthcare directives legally binding but they have provided for a ‘proxy document’ or a power of attorney to give a named person the authority to make decisions on the patient’s behalf. Also in Scotland, in contrast to the Irish legal view, they do not generally recognise artificial nutrition and hydration as a treatment and as such ANH cannot be refused as a treatment. It is seen as part of basic care which is not normally covered under an advance directive. ANH is considered providing humane assistance and providing for the welfare of the patient. It has however been shown in some cases of PVS patients that the burden of continuing ANH outweigh the benefits of continued existence in a vegetative state. In Ireland ANH is considered to be a medical treatment and as such can be refused by a patient. There is the possibility of legal recognition for an
advance statement under the Mental Health (Care and Treatment) (Scotland) Act 2003 (2003b) but this only covers treatments for mental disorders.

3.1.4 Development of Advance Healthcare Directives in Ireland

In Ireland the Law Reform Commission (Irish Law Reform Commission, 2009) produced a report on advance healthcare directives. It stated that while there needs to be recognition of less formal means of preparing an advance healthcare directive it is still crucial that the patient understands the consequences of refusing treatment, in particular, life-sustaining treatment. Nowadays with easy access to many forms of information people can find out about their health condition by looking it up on the internet. The patient’s doctor may no longer be the only source of information available to the patient. So when a patient makes a decision which would not be recommended by a healthcare provider, their decision to refuse treatment should still be upheld even if it is thought by others that it is unreasonable. The Supreme Court in Ireland made this point clear in their judgement in re a Ward of Court (No 2) (1996b) that even where treatment can sustain life the patient still has a right to refuse that treatment even if it goes against medical advice and it does not need to be based on logical or rational reasons. The refusal can also be based on religious grounds, like Jehovah’s Witnesses not wanting any blood transfusions. In its judgement the Irish Supreme Court also recognised that artificial nutrition and hydration was a medical treatment. This case and these decisions impact on the development of legislation covering advance healthcare directives in recognising a patient’s right, in certain circumstances, to refuse treatments, that ANH is a treatment which can be refused, and a person can make informed decisions to refuse life sustaining treatments.

3.1.5 Our new proposed legislation
There are still a few stages for the Assisted Decision-Making (Capacity) Bill 2013 to get through the Dáil.

1. Committee Stage
   Recently published proposed amendments on 17th June 2015
2. Report and Final Stages
3. Seanad Éireann – for discussion and ratification
4. It may go back to steps 1 and 2
5. Final Stage
6. Enacting as Act

There may be many or few amendments at each of the above stages. I assume that as a guide that it will not be altered drastically from what has been presented by authorities from the Department of Health (Irish Hospice Foundation, 2014a) and the recently published list of amendments (Select Committee on Justice Defence and Equality, 2015).

The advance directive section of the new proposed legislation covers:

Definitions:
A definition of ‘advance healthcare directive’:

a) in relation to a person who has capacity, means 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 and

b) In relation to a designated healthcare representative, means the advance expression referred to in a) under which the representative was designated as a representative, which has not been revoked.

A designated healthcare representative is defined as ‘the named individual designated by the directive-maker, in his or her advance healthcare directive, to exercise the relevant powers’.

‘Directive maker’ means the person who made the directive.
‘Relevant powers’, in relation to a designated healthcare representative means

a) The power conferred on the representative to ensure that the terms of the advanced healthcare directive are complied with.

b) One or both of the following powers may be conferred on the representative under the advance healthcare directive to

1. Advise and interpret what the directive-maker’s will and preferences are regarding treatment as determined by the representative by reference to the relevant advance healthcare directives

2. Consent to or refuse treatment, up to and including life-sustaining treatment, based on the known will and preferences of the directive-maker as determined by the representative by reference to the relevant advance healthcare directive.

‘Treatment’ means an intervention that is or may be done for a therapeutic, preventative, diagnostic, palliative or other purpose related to the physical or mental health of the person, and includes life-sustaining treatment.

‘Director’ is a person appointed by the Courts Services, to be known as the Director of the Decision Support Service, to perform the functions conferred by the Act. This includes the implementation and the supervision of compliance with the Act.

‘Minister’ means the Minister of Health to whom the Director reports. The Minister may provide guidance and specific forms to the public for the purpose of making advance healthcare directives. The Minister may require the Director to establish and maintain a register of advance healthcare directives.

**Setting up an Advance Healthcare Directive**

The purpose of an advance healthcare directive is to
1. Enable a person to be treated according to their will and preferences and

2. Provide healthcare professionals with important information about persons in relation to their treatment choices.

To make an advance healthcare directive the relevant person must

1. Have attained the age of 18 years and

2. Have capacity.

The directive shall be in writing and shall contain the following

1. Name, date of birth and contact details of the directive-maker

2. The signature of the directive-maker and the date of signing or it may be signed on behalf of the directive-maker by a adult person who is not one of the other witnesses if

a) The directive-maker is unable to sign

b) The directive-maker is present and directs that the directive be signed on his behalf by that person

c) The signature of that person is witnessed

3. The signature of the directive-maker, or the person signing on his or her behalf and the designated healthcare representative shall sign the advance directive in the presence of each other (where applicable) and in the presence of 2 witnesses, each of whom has attained the age of 18 years age and at least one of them is not an immediate family member of the directive-maker.

4. Each of the witnesses shall witness the signature of the directive-maker (or the person signing on his or her behalf) and the signature of the designated healthcare representative by signing the advance healthcare directive.

5. The directive may be revoked by the directive-maker once they have capacity at any time in writing.
6. The directive may be altered by the directive-maker when they have capacity at any time in writing following the same signing process as above.

An advance healthcare directive entitles the relevant person to refuse treatment for any reason (including a reason based on his or her religious beliefs) notwithstanding that the refusal

   a) Appears to be an unwise decision which is contrary to medical advice
   b) Appears to contradict sound medical principles, or
   c) May result in his or her death
   d) Contradicts the wishes of family who wish to go to extraordinary lengths to keep their loved one with them.

A refusal of treatment set out in an advance healthcare directive shall be complied with if the following conditions are met:

1. At the time in question the directive-maker lacks capacity to give consent to the treatment,

2. The treatment to be refused is clearly identified in the directive,

3. The circumstances in which the refusal of treatment is intended to apply are clearly identified in the directive.

A request for treatment in an advance healthcare directive is not legally binding but shall be taken into consideration during any decision-making process which relates to treatment for the directive-maker if that specific treatment is relevant to the medical condition for which the directive-maker may require treatment.

If a healthcare professional involved in the decision-making process does not comply with a specific request for treatment set out in the advance healthcare directive, they shall
1. Record the reasons for not complying with the request in the directive-maker’s healthcare record, and

2. Give a copy of those recorded reasons to the person’s designated healthcare representative (if any) as soon as it is practicable though not later than 7 working days after they have been recorded.

Register an advance healthcare directive

After making an advance healthcare directive, a directive-maker shall be required to notify the Director, or other specified person, to allow for the directive to be registered on a national register of advance healthcare directives. The Director is required under the proposed new legislation to establish and maintain a register of advance healthcare directives. The Director, under the legislation, shall also promote advance healthcare directives and build public confidence, with the distribution of information and guidance in the form of the code of practice to support major groups affected by the new legislation.

A valid and applicable advance healthcare directive

In section 58 of the Act, the directive may be deemed invalid if

1. It was not made voluntarily

2. The directive-maker did not have capacity when making the directive

3. The directive-maker has done anything which would be inconsistent with the values stated in the directive.

The directive may be deemed not applicable if

1. The directive-maker still has capacity to make their own healthcare decisions

2. The directive does not address the specific treatment in question
3. The treatment specified in the directive does not clearly state when it should be applied and in what circumstances.

The directive does not apply to life-sustaining treatments unless specifically stated in the directive that the directive-maker understands the risk to his/her life.

The directive does not apply to basic care which includes warmth, shelter, oral nutrition, oral hydration and hygiene but it does not include artificial nutrition and hydration.

If there is any ambiguity about the directive being valid or applicable it shall be resolved in favour of preservation of life.

A healthcare provider may also try to resolve any ambiguity by consulting with

1. the directive-maker’s healthcare representative (if there is one)
2. family and friends
3. other healthcare professionals

If the directive-maker is pregnant the directive may not apply if

1. the directive has not specified what she wants in the case of pregnancy. Where the refusal of treatment would be possibly harmful to the unborn there is a presumption that life-sustaining treatment shall be provided or continued.

2. the directive has specified a refusal of treatment even in the case of pregnancy, where the refusal of treatment would be possibly harmful to the unborn, then an application may be made to the High Court to verify if the directive should apply.

If the directive-maker’s treatment relates to a mental disorder which does not require the patient’s consent, as specified in the Mental Health Act (2001a), where treatment is required to safeguard the life of the patient, the directive should not be complied with. However if the refusal of treatment relates to a
physical illness unrelated to the mental disorder, the refusal should be complied with, as in the case Re C (Adult Refusal of treatment) (1994).

**Effects of an advance healthcare directive**

Apart from making a directive-maker’s refusals of treatment legally binding, if they are valid and applicable, the directive does not impose any civil or criminal liability on healthcare professionals when complying with a directive they believe to be valid and applicable, or where they do not comply with a directive they believe to be invalid or not applicable. There is also no civil or criminal liability on healthcare professionals who do not comply with a directive because

1. they did not know a directive existed or
2. if they knew a directive existed but were unable to access it or access it in a timely manner in an case where urgent medical treatment was required.

An advance directive may not request or refuse any treatment which is considered unlawful relating to murder, manslaughter or suicide (1993b).

**Designated Healthcare Representative**

As previously stated the designated healthcare representative exercises the powers provided for in the directive by the directive-maker. The designated healthcare representative agrees and confirms their willingness to act on behalf of the directive-maker by signing the directive.

The designated healthcare representative must

1. have attained the age of 18 years and have capacity to exercise the relevant powers
2. not have been convicted of any offence in relation to the directive-maker or the family of the directive-maker
3. not have any safety or barring order in relation to the directive-maker or the family of the directive-maker
4. not be an owner or registered provider of a nursing home where the directive-maker resides unless the individual is a spouse, civil partner, cohabitant, parent, child or sibling of the directive-maker

5. not be paid to provide personal care or healthcare services to the directive-maker unless the individual is a spouse, civil partner, cohabitant, parent, child, sibling or primary carer of the directive-maker.

If after being designated in the directive any of conditions 1 to 5 above no longer apply to the designated healthcare representative the individual shall no longer be allowed exercise the relevant powers.

The designated healthcare representative who is the spouse, civil partner or cohabitant of the directive-maker may no longer be allowed exercise the relevant powers if they subsequently separate, divorce or cease to cohabit for more than 12 months.

There is also no civil or criminal liability on the designated healthcare representative who acts in good faith and acts in accordance with the will and preferences of the directive-maker.

The designated healthcare representative shall record in writing any relevant decision taken on behalf of the directive-maker. These records must be available to the directive-maker (if they regain capacity) and the Director upon request. The Director may review any compliant he/she receives. The Director may then decide if an investigation is warranted. After completing an investigation the Director may, if it is appropriate, refer the matter to the courts.

The designated healthcare representative may only exercise the relevant powers for as long as the directive-maker lacks capacity. The designated healthcare representative is not allowed to delegate any of the relevant powers.

The directive-maker may also designate an alternative designated healthcare representative in the case the first one dies, is unable or declines to act. The
alternative individual must also qualify to act as a designated healthcare representative.

Role of the Director
The Director may receive queries concerning advance healthcare directives with regard to

1. actions or omissions made by the healthcare professionals
2. actions or omissions made by the designated healthcare representative
3. whether an advance healthcare directive is valid or applicable

The Director shall

1. review the query, and if it has substance shall conduct an investigation
2. upon completion of the investigation the Director may decide to
   a. take no further action
   b. make an application to the relevant court
3. The relevant court may then decide if
   a. The healthcare professional is complying with the advance healthcare directive and acting in accordance with the code of practice
   b. The designated healthcare representative is behaving in accordance with the advance healthcare directive
   c. The advance healthcare directive is valid and applicable

So in conclusion we can see the direction of our proposed legislation is similar to that taken in UK. We have the ‘proxy’ decision maker (similar to Scotland) and the legal refusal of ANH (similar to England). We have taken account of cases and legislation in UK as well as cases here in Ireland. I believe that our new proposed legislation covers many of the recommendations put forward by the LRC in its report (Irish Law Reform Commission, 2009). Our Law Reform Commission refers to the Mental Capacity Act 2005 in England and offers a similar structure to our new proposed legislation. The LRC advances an additional proposal in setting up a register of advance healthcare directives, similar to that set up in the U.S.,
which would of course only be relevant to written advance healthcare directives. The development of such a register is proposed to be included in Ireland’s Code of Practice on Advance Healthcare Directives.

The LRC recommended that ‘if a reasonable doubt exists as to the validity or meaning of an advance healthcare directive, any such doubt must be resolved in favour of preservation of life’.

In jurisdictions like the U.S. and the UK where advanced care directives are made, they may be in writing but there is no obligation to communicate them to the relevant healthcare profession. Due to the informality of an advance healthcare directive it may be possible that a physician is not aware that you have one, or if you have made recent changes to it. It should be part of the Code of Practice for setting up advance healthcare directives that a patient would be encouraged to have it in writing and registered with the Director and the national register for advance healthcare directives. This could avoid failure in accessing an advance healthcare directive during out of hours when it would be difficult to contact the patient’s GP or for him/her to access their files. It is the best argument for the setting up of a national registry of advance healthcare directives as it would ensure 24 hour access to advance healthcare directives at all times.

The informality of advance healthcare directives also brings issues of judging the validity and applicability of the instructions. Especially in cases where the instructions are based on verbal evidence it may be difficult to assess whether the instruction is valid, as in the case discussed earlier – W Healthcare NHS v H (2005b), that the patient was making an informed decision, that the decision is applicable in the circumstances, or that the instruction covers the specific treatment decision required at the time. In the past these judgements can be heavily influenced by a medical professional’s opinion and the judge’s view of the patient’s best interest. To secure the best possible chance of gaining full respect for the patient’s autonomy and the directives they make, the instructions should be as clear as possible, dealing
with specific treatment options, providing the reasoning behind the decision to allow the physician or judge to understand why the decision was made.

The validity of the advance directive may also be questioned based on the reasonable outcome of choice test, where the author made a choice in the advance directive that appears to be an irrational choice. The author’s competence when making the directive may be questioned and thus render the choice made in the advance directive invalid. To avoid this problem of guessing at the competence of the author at the time the advance directive was made, a written statement of competency may be included.

It is important to be as informed as possible about healthcare issues you may face in the future, knowing what treatment options may be available and their consequences and risks for you when making a valid and applicable advance healthcare directive.

Selecting a healthcare representative is very important and should be done with great care. There are very few safeguards in an advanced directive to protect the individual from the wishes of the healthcare representative being implemented instead of the wishes of the patient. Also the selected representative should be able to shoulder the burden of surrogate decision-making on behalf of the patient.

Reviewing and updating your advance healthcare directive is also important in avoiding the directive being challenged. It is important to record if you have had a change of mind about some or all of the decisions made in your advance healthcare directive. It may not be necessary to amend the directive but only just to have it dated that you have reviewed it and acknowledge that the directive still reflects your values and preferences. Well meaning family, friends, healthcare professionals and indeed even judges in the courts may decide to overrule an advanced care directive out of concern for the patient’s welfare or uncertainty whether a directive is out of date and no longer reflects the wishes of the patient. This recommendation for a regular review is not required under the UK Mental Capacity Act and it is up to the author to decide when, how often or if to review the advance healthcare directive.
Patients may rely on an advance directive to indicate what they cannot say even when they have capacity. They may feel so inhibited about discussing death and dying that they prepare the advance healthcare directive in isolation, without any reference to others. So instead of encouraging an open discussion of their wishes with their doctor, family and friends, it may help the individual avoid talking about the issue altogether.

So to summarise, to make a valid and applicable advance directive it must be

1. Made when the person is competent
2. Covers the situation that may arise
3. Patient has not changed his/her mind.

In principle individual autonomy may be primary but in practice other values may outweigh it

1. Sanctity of life – opting for the preservation of life
2. Patients welfare – care and pain management
Chapter 4

4.1 How can we guide implementation of the new legislation?

4.1.1 Guidelines – Code of Practice

Code of Practice
Under our new proposed legislation the Minister shall establish a multidisciplinary working group to make recommendations to the Director to assist in the preparation of a code of practice. The prepared code of practice will then go back to the Minister for final approval.

The Code of Practice for the Mental Capacity Act 2005 (Lord Chancellor, 2007) in England gives us some guidance on the implementation of advanced care directives.

In their code of practice ‘Healthcare professionals must follow an advance decision if it is valid and applies to the particular circumstance’ or they may face charges or may even be sued.

The Mental Capacity Act in England, under section 26, also provides protection for healthcare professionals from liability when they are not satisfied that an advance decision exists which is valid and applicable to the treatment. Their Code of Practice notes, ‘it is ultimately the responsibility of the healthcare professional who is in charge of the person’s care’ to determine whether there is a valid and applicable advance directive. The test of ‘satisfaction’ is open to the subjective discretion of the professional and if there are ‘any doubts about the advance decision’s validity or applicability, they may treat the person without fear of liability’. This may mean that only the most certain, exact and specific advance decisions may prevail. The provision of healthcare is facilitated and patient welfare is protected but respect for patient autonomy may be diminished.

The Irish code of practice set up under the new legislation by the Director, after a consultation process with a working group of experts and with the
consent of the Minister, is likely to be influenced by some aspects of the English Code of Practice, but is also likely to be influenced by the recommendations from the LRC (Irish Law Reform Commission, 2009). I hope that we can provide adequate support for individuals to make a valid and applicable advance healthcare directive in order for their autonomy and wishes to be respected as fully as possible.

The LRC had many recommendations with regard to the new legislation but also for the new Code of Practice. The new Code of Practice would provide necessary guidance for many aspects of the new legalisation which, are not limited to but, may include

1. Definitions on care, palliative care, basic care as well as life-sustaining treatments
2. Unwritten, verbal or recorded advance directives, or even organ donor cards or blood cards carried by Jehovah Witness which may not necessarily be registered with the central database
3. Suitable forms which may be used for advance healthcare directives
4. Assessment of capacity when making or activating an advance healthcare directive
5. Dispute resolution between, healthcare professionals, patient representatives, families and other interested parties
6. Resolving differences which may arise between EPA and advance directive.

4.1.2 Central database of registered advanced care directives.

The new legislation proposes that the Director shall establish and maintain a register of advance healthcare directives which have been notified to him or her.

The availability of patient’s electronic records and especially advance healthcare directives in a central database facilitates access by healthcare professionals from the patient’s GP, to out of hours GP services, to emergency assistance at A&E Hospital sites in recognising and implementing advance healthcare directives.
This proposed database system would facilitate access to a person’s advance healthcare directive. What happens if the database is down and not accessible? What happens if the copy of the advance directive is not as up-to-date as the one recently reviewed with the patient’s GP and is only available at the GP’s office? What happens if you have prepared your own advance healthcare directive and only have it in your home and family or friends cannot find it. What happens if you are travelling abroad, have a catastrophic accident and can’t access your national database of advance directives? All these questions raise the problem of access to your advance healthcare directive. It will only be possible to implement your advance healthcare directive if those treating you know that it exists and can access it. The implementation of your advance healthcare directive will depend greatly on whether it is up-to-date and accessible to the healthcare professional looking after your care. The implementation plan should include several options on how to

1. access the advance healthcare directives
   a. bring a copy with you
   b. have an electronic version accessible online
   c. telephone access to a central call centre for the register of advance directives etc

2. update or revoke it if necessary with the Director and the new register of advance directives.

4.1.3 Surveys conducted in Ireland

One successful information and education plan was initiated by the Irish Hospice Foundation called the Hospice Friendly Hospitals (HFH) Programme in 2007 to help develop standards in hospitals dealing with end-of-life care. It aims to promote high quality care for all people at the end of life by highlighting the role of clinical, administrative and support staff in improving the patient’s and family’s experience. The survey noted that nearly half of the annual deaths in Ireland (43%) occur in acute hospitals (Irish Hospice Foundation, 2004). The Irish Hospice Foundation has many seminars and
conferences educating healthcare professionals and lay people to improve the culture of dying, death and bereavement in hospitals and in society as a whole. As part of their education programme they provide many resources and publications one of which is their ‘End of Life Care Map’ (Irish Hospice Foundation, 2012). They promote discussion and engaging the patient in advance decision making for the likely course of their future healthcare. This ‘Care Map’ helps the clinical staff deal with patient care and offers some practical advice on communicating with patients and their families and their education in making future healthcare decisions. In another survey, carried out by Joan McCarthy in 2010 which was undertaken to help achieve the aims of the HFP (McCarthy et al., 2010), it concluded that ‘educational interventions, public and organisational policies and legislation are needed to address the uncertainty that surrounds the role of professionals and families in making decisions for the dying patients’.

‘Think Ahead’ – Advance Healthcare Directive Forms

The IHF have also developed an important tool, the ‘Think Ahead’ document which is very useful in formulating and documenting your wishes for the time when you may lose capacity (Irish Hospice Foundation, 2014b). It includes sections on

1. Healthcare and welfare preferences
2. In Case of Emergency
3. Legal affairs
4. Financial affairs
5. Funeral arrangements
6. Who should have access to my information? – protection of privacy

It encourages communication with

1. a solicitor on putting your legal affairs in order
2. Your doctor on medical treatments which you may wish to have or not have

3. Trusted friend or family member who may make decisions on your behalf when you cannot

4. Other family members and friends so you may explain your decisions or possibly review and amend the advance directive.

After documenting your advance directive the next most important step in the implementation of your advance directives is to have it recorded on your medical record or registered in such a way that it is easily available to healthcare providers not only in your current care environment but for emergency situations.

To keep your advance healthcare directive up-to-date is very important so that it continues to reflect your specified preferences. I would recommend that a good opportunity with be at a regular annual check up at the GP with a facility to send it on to the register of advance healthcare directives.

In effect an advance directive has limitations in its implementation but if it stimulates discussion of advance healthcare planning between the person and their family, close friends and their healthcare providers it plays an important role in providing information and education to all concerned. It protects the principle of ‘informed consent’ in respecting patient autonomy and self-determination.

In the new legislation it is proposed that the Minister may specify forms of such directives, consistent with the legislation, to guide anyone wishing to make an advance healthcare directive. The Minister may also publish any forms of advance healthcare directives in such a manner as he or she thinks appropriate, which may include the use of a website on the internet.

The means of promoting advance healthcare directives is at the primary healthcare contact with the public. The Irish Hospice Foundation carried out a pilot project, using their ‘Think Ahead’ document in GP practices. An ‘Acceptability Study’ was carried out in a GP setting, lead by Dr. Brendan
O'Shea (O'Shea, 2014). The document was given to healthy, middle aged patients to fill out. It opens up the conversation about death and dying. It offers some certainty to the uncertainty of leaving the decisions to someone else. Discussing your wishes allows your family and friends to come to terms with your inevitable death. It helps enormously with their grieving and sense of loss after your death if they know that your final wishes were respected and you died with dignity.

The feasibility study was carried out in 2011 to 2012. It included 100 patients in 5 GP practices. The selection criteria were for participants who were stable patients with no significant medical illnesses. They were only coming into the GP for blood pressure check or HRT prescription, or eye test for driving license etc. Unstable patients were excluded.

The survey participants were firstly advised and informed about the survey, they would:

1. fill out the ‘Think Ahead’ document
2. be encouraged to talk about it to their ‘best friend’
3. receive a telephone survey at 1 week and again at 3 weeks to check on progress of completing the form

The purpose of the survey was to assess the ‘Think Ahead’ document for patient’s acceptability and perceived usefulness. Was it useful or could it be refined?

The participants were approached at the GP Practice and provided with an information sheet. They were advised about the study and invited to participate. If they agreed they were given the ‘Think Ahead’ document to take home and informed written consent to agree to participate in the survey was obtained.

Then the telephone surveys were conducted and the following questions were asked.

1. Did you read it?
2. Did you complete it?

3. Did you find any parts of it difficult?

4. Was it upsetting?

5. Was it of interest when filling it out?

6. Did you discuss it with anyone? This was an important indicator for the survey on engagement with family and friends on its effectiveness.

7. Was it OK to be given 'Think Ahead' when coming into GP?

8. Would you like it to be on the internet or do you prefer paper form?

Some key findings of the survey in brief:

1. More female than male participants – this was a general sample of the population

2. Medical card v private – as expected, reasonably representative of the Irish population

3. Should ‘Think Ahead’ be more widely introduced?
   a. 86% Yes

4. Was it difficult to understand?
   a. 63% No difficulty
   b. Minority had difficulty around some issues like CPR and ventilation
   c. Some legal issues or key issues were challenging to a minority of participants

5. Should it be changed?
   a. >80% it was fine
   b. Some changes/clarifications would be welcome
i. The section on who should be advised could be expanded on

ii. How often the document should be reviewed, advise on regular reviews

iii. Church and religious organisation should be notified in cases where participants had stated preferences

6. Has reading this caused you to discuss your end-of-life with family?
   a. 85% it did
   b. 15% it didn’t
   c. <50% discussed the issue in detail
   d. <40% discussed somewhat

7. Was it upsetting? (Key question)
   a. 75% it was not upsetting
   b. 25% some parts caused upset. This was around topics like organ donation and switching off life support which some participants found upsetting.

This can be compared to the upset dealing with distressed family members where there is no advance healthcare directive, where decisions are being required from emotional and vulnerable relatives of a patient in a terminal event.

8. Were there any areas you found difficult to complete?
   a. 6% found making a will was difficult to formulate correctly without some assistance
   b. Some found details around dying were difficult emotionally
   c. 3% found the finance section was difficult to understand
d. 3% found the issue around CPR was difficult to evaluate

It was easier to discuss these issues when you are well. It is difficult to discuss these issues when you are dying.

9. Would completing this document be of interest to other people?
   a. 65% Yes
   b. 21% No Opinion
   c. 4% No it wouldn’t

10. Should it be introduced more widely?
   a. 86% Yes

Overall it was a small but representative study which provided some very positive feedback. There was good engagement, participants were happy to take it, fill it out and give feedback. It fitted in well with the GP practice. As a tool it is self-explanatory and by prompting discussion it promoted a better understanding of healthcare decisions at end-of-life. The GP practice is a good place to distribute and promote it systematically to the general public. It does not appear to impact hugely on the GP workload in the initial discussion and handing out the document but of course the follow up phone calls which were conducted for the pilot project required a greater commitment of time from the GP. Alternatively the follow up may be postponed until the patient is in again to see the GP.

A few weakness of the study were identified

1. Only a small number of questions
2. The sample was small – 100 participants
3. Response bias – the doctor giving out the Think Ahead document was the one calling up on the telephone. Patients may not have wanted to upset their doctor.
After this study they carried out an educational intervention with staff in 5 nursing homes in Kildare. They had a sample of 500 patients and discovered that only a small number of patients had clearly recorded end-of-life planning. Patients were to be reviewed again after 4 months in 2014. The results were published in the British Medical Journal in 2015 (McGuinness et al., 2015). The conclusion of the research and educational projects was a very positive. 80% of the public believe that Think Ahead would be of interest to them, with GPs and nursing home staff feeling empowered in enabling patients and residents to express their preferences.

Next, it is proposed to have a blended learning pack to help doctors and nurses to engage in these conversations more easily.

The recommendations of these studies and surveys are:

1. To recommend to all 50+ to fill out a Think Ahead document and that the GP is a good place to distribute them. There are also other good places like nursing homes, community centres and hospital clinics.

2. Everybody with a significant medical diagnosis should be asked to consider filling out ‘Think Ahead’. Not on the day that they are given the diagnosis but later at a 6 or 12 week visit. It should be part of good chronic disease management for 50+ and hypertensive patients.

3. When being admitted to a nursing home or a supportive care environment it should be part of the 6 to 12 week follow up.

It is best done in the company of a good friend or family member with relevant input and advice from professional advisors especially the trusted GP who knows the health history of the patient very well and can assist and guide the patient as circumstances change.

‘Think Ahead’ has been found to be a valuable tool and is free to everyone. It is available on the Irish Hospice Website http://hospicefoundation.ie/programmes/public-awareness/ or direct at their website http://www.thinkahead.ie/. See Appendix at the end of this dissertation for a copy of the ‘Think Ahead’ form.
4.1.4 Promoting and discussing advance healthcare directives

How do we promote advance healthcare directives not only to the elderly in our communities but also to healthy young people to be prepared not only for terminal or fatal illness but for accidental injury where capacity is lost? As we have seen from cases which have come before the courts there are many instances of PVS and loss of capacity after a sudden illness or accident in young people. I believe people should be empowered to write an advance healthcare directive when they become 18 and have capacity to do so. In the event of tragic circumstance where they lose capacity their previously stated wishes could guide decision making regarding their care. As we have seen, it is mostly the elderly that take the time to think about death and dying and make a 'living will'. The young and healthy still feel that such plans may not be relevant to them or are too busy with their lives and do not plan for the time they consider to be too far into the future to worry about.

The previously successful advertising campaigns for ‘stopping smoking’ could provide a blue print for similar campaigns on advance healthcare directive. Would it be possible to promote advance healthcare directives in such an aggressive way? Unfortunately I must answer no, but there is potential in an advertising campaign to heighten awareness of advance healthcare directives. The advance healthcare directives are promoting patient autonomy not a major public health concern. It is a voluntary process which, though a ‘good idea’, is not obligatory. To support and assist the general public in gaining knowledge about advance healthcare directives, discussing them with others and making and reviewing an advance healthcare directive an implementation plan will be needed.

The promotion of advance healthcare directives is based partly on the informality of the steps involved. Few procedural formalities encourage everyone to think about the options of what care they would wish to have, or to refuse, in certain circumstances and to simply state them to a friend or family member, by recording them verbally, or writing them down. This is a
simple means to protect and respect patient rights and autonomy under the proposed legislation. Even though the legislation stipulates that a valid advance healthcare directive must be in writing, for some disabled individuals this may include dictating their advance healthcare directive or recording it on video. The new register would then also have to accommodate the storing of video and audio files as well as electronic word or pdf documents.

The recommendation to have refusals of life sustaining treatments treated more formally is essential to protect vulnerable patients.

Advance healthcare directives may be set up well in advance of when they may come into effect. Due to the passage of time I need to consider the possibility that my values or preferences may have changed. I need to consider reviewing my advance healthcare directive on a regular basis. At the time of an annual GP medical check up might be a good time to do this review. Also having a ‘designated healthcare representative’ who knows me well and sees me regularly would protect against the advance directive going out of date. I would hopefully have discussed any changes to my values and preferences with my representative.

Making informed decisions in an advance healthcare directive is not as easy as it may sound. Lin and Fegerlin (Lin and Fagerlin, 2014) in their article on ‘Shared Decision Making’ found there were many obstacles to open and full communication between patients and healthcare professionals. This may include misunderstandings brought about by general statements like ‘heroic measures’, ‘decent quality of life’ and ‘dignified death’ which are all very subjective for the person, that it is difficult to translate them into actual clinical treatments. They introduce 9 elements or processes involved in sharing information and making a decision.

1. Defining and explaining the problem – this would be exploring the type of treatments to be considered in an advance healthcare directive.

   a. In case of terminal illness
b. In case of emergency

2. Presenting options – what options are available for the types of interventions available, also exploring the possibility of future as-yet-unknown options.

3. Discussing the pros/cons/costs of the various options – very important for patient to understand the balance of risks and possible benefits of not only the treatment itself but also any and all relevant side effects.

4. Sharing patient values and preferences – this may be based on cultural influences.

5. Discussing patient ability and self-efficacy – levels of capacity, ability to make certain decisions. This could be the current level of capacity and well as the future level of capacity due to the progression of an illness.

6. Offering medical knowledge and communication – at a level the patient can understand. Plain simple English should be used in all documentation and using creative design models and other graphical aids to demonstrate areas of the body under discussion all help in the delivery of information and understanding by the patient. This process helps promote patient health literacy.

7. Checking and clarifying understanding – more time may be needed where education is low

8. Making a decision or deferring it, to allow the patient to return to the decision at a later time after further consideration.

9. Arranging follow up

All of the above processes have noted limitations, like the time available either to the patient or the healthcare professional, the communications skills of both the patient and the physician, the education levels and numeracy levels of the patients to understand the health information being provided.
Recommending medical counselling in preparing an advanced care directive places some emphasis on ‘informed consent’ and ‘patient autonomy’ however not making it a formal requirement allows the subsequent directive to become vulnerable to challenge and undermines the ‘patient autonomy’ it was intended to protect. Making it easier to make an informal advance healthcare directive allows a person a simple format to make their wishes known but we also need a formal procedure of signing a written document and having it witnessed to protect the author from the risk of undue influence or pressure at the time of making the directive.

Many older people may have little previous knowledge of living wills – only 2% according to a survey carried out in 2000 in UK, but many may be very interested in the concept, and 92% indicated when they would no longer wish to opt for life-prolonging treatments (Schiff et al., 2000)

In 1989, in a US survey of physician’s attitudes on advance directives nearly 80% of physicians surveyed in Arkansas expressed a positive attitude about advance directives (Davidson et al., 1989). Over 55% of physicians had actual experience of assisting patients setting up advance directives in their practice. 83% of whom, were very positive about advance directives after their experience of employing an advance directive in critical situations. Most of the benefits attributed to advance directives were supported by the survey:

1. Improved communication and trust
2. Easier and more confident treatment decision
3. Less stress and guilt
4. Promotion of patient autonomy

Advance healthcare directives provide benefits to patients especially with decisions around CPR and DNR or DNAR which should be discussed in a full and early stage of aging, before dementia or other debilitating illness affect the patient’s capacity to make decisions for themselves. The discussion should include education for the patients on the process of CPR and its levels of success, risk and burden and also for the physician to gain an
insight into the patient’s levels of knowledge, understanding and preferences. (Cherniack, 2002)

Better quality of life in the week before death predicts improved bereavement adjustment among caregivers of patients with advanced cancer. Medical orders like DNRs are associated with better patient quality of life in the week before death indicating that documenting patient preferences is beneficial not only to many patients but their families and caregivers as well. (Garrido et al., 2015)
Conclusion

The initial question posed in the title of this thesis was ‘Advanced Care Directives – Friend or Foe?’

In the body of the thesis I have tried to look at who Advance Healthcare Directives are useful for by specifically looking at the following groups in society

- society in general,
- patients in general, or
- certain groups of patients,
- for healthcare professionals and support staff looking after patients,
- for the families who may not be burdened with the responsibility and stress of making difficult decisions for their loved ones?

Without doubt, analysis of the topic has shown advance healthcare directives are not without problems or challenges as they can be difficult to interpret if the patient’s wishes are unclear and cannot be implemented if they go against clinical advice and practice or even against justice to all patients in resource management.

As with many tools they are only as good as the person using them. It is apparent from the literature that for advance healthcare directives to be useful and effective that information and education are vital in providing an individual with the knowledge to set up an advance healthcare directive. A simple and easily accessible format is needed to document and register the advance healthcare directive. Safeguards can be put in place, like the witnessing of the document to ensure capacity and understanding of the document. Also the proposal to develop an authority like the Director, of the Decision Support Services, to review and regulate the register of advance healthcare directives and process any complaints made under the Act, is vital to ensure compliance with the law as well as ensuring ongoing benefit and usefulness to the individual. A healthcare representative could be extremely useful in that they can stand in for the patient when specific situations which are not covered in the advanced care directive arise. Lastly, the patient needs to get involved in the discussion with healthcare providers, family and friends to enable the proper implementation of the patients’ wishes.
Advance healthcare directives do not exist in isolation. They are imbedded in legislation connected to mental health, in England and Wales – the Mental Capacity Act 2005, in Scotland - the Mental Health (Care and Treatment) (Scotland) Act 2003, and now in Ireland – the Assisted Decision-Making (Capacity) Bill 2013. In our ‘Think Ahead’ document, it is put forward as a part of putting all my affairs in order, including legal and financial documents. In ‘Think Ahead’, making a will and setting up an enduring power of attorney are included as part of the overall document. In the new legislation the advance healthcare directive is separate from wills and EPAs. The ‘Think Ahead’ document is very welcome in its overall approach to planning ahead and putting your affairs in order, but a separate form or document will be needed to comply with the conditions laid down in the new proposed legislation. We can of course borrow from the simple, well laid out structure of the ‘Think Ahead’ form in preparing the new advance healthcare directives.

It should be at government level and not just on voluntary organisations, like the Irish Hospice Foundation, to promote advance healthcare directives. It would require national advertisement campaigns, education on the responsibilities of people who wish to make an advance healthcare directive, on the healthcare professionals to support those making informed decisions about the healthcare they wish to have or refuse in the future.

The new legislation introduces something new in disqualifying a spouse or partner from being the designated healthcare representative if they become divorced, separated or no longer co-habiting with the directive-maker. It specifies that one of the witnesses signing the advance healthcare directive is not a close family member, where in England they specified that one of the witnesses could not be eligible to inherit from the directive-maker. These are all good safeguards for the protection of vulnerable individuals when preparing their advance healthcare directive.

So to answer the thesis question ‘Advanced Care Directives – Friend or Foe?’, I must answer that they can be a very good friend if used and implemented properly. Proper safeguards must be put in place through
legislation, education and promotion of public awareness campaigns so they do not become a Foe, with unwanted and undesired outcomes for patients, their families, healthcare professionals and society at large.
Recommendations
The proposed legislation covers most of the recommendations from the LRC.

It does not seem to cover the option of unwritten directives; this may be especially important where we have seen cases of disability with limited means of communication. The LRC recommended that an EPA may take priority over an advance healthcare directive, but the legislation did not cover this eventuality, but instead referred to any unresolved ambiguity to be taken to the relevant court for final arbitration.

The legislation has provided for an authority to help set up, implement and regulate the powers of the Act. The Director of the Decision Support Services has a lot of work to do in setting up the new services but also in setting up the new Code of Practice. The LRC provided many recommendations with regard to the Code of Practice which may be given due consideration by the working group, to be established by the new legislation, to provide recommendations for the Code of Practice to the Director.

After reviewing many types of advance healthcare directives available I was very impressed with the online version set up by Levi and Green in the US. It was very effective in providing information and educating the user about the possible healthcare decisions which may be needed in a step by step approach to set up an advance healthcare directive. Asking simple questions on quality of life and preferences with a ‘very important’ to ‘least important’ sliding scale and translating these preferences into a written advance directive which would be understandable to the healthcare providers. It seemed to address many of the concerns raised over the years of using advance healthcare directives in the US. This would probable need some adjusting to our Irish legislation, Irish healthcare systems and culture but it is an excellent tool which is simple and easily accessible to the public. The US seemed to focus more on the advance healthcare directive as a standalone entity and even though it may be difficult to keep it concise the ideal of ‘putting all my affairs in order’ with the ‘think ahead’ document is also very appealing.
The Director may look to the US when setting up a register of advance healthcare directives following the easily accessible format and protection of privacy and confidentiality. Simple and safe access, not only by the healthcare providers but also, by the individual will have to be provided to allow the directive to be modified or revoked when or if needed by the directive-maker.

The large code of practice for the Mental Health Act 2005 in England may provide a reference point for setting up our own code of practice for our assisted decision-making capacity legislation, but it will also need to be translated into bite size parts for public education and information leaflets.
Appendices

Samples of Advance Care Directives

Computer based – Advance Directives from Penn State College of Medicine

Sample of screenshots of webpages
Making your Wishes Know

Main Webpage – www.makingyourwishesknown.com
Introduction webpage – information on the student project which was completed by Dr. Levi and Dr. Green.

Introduction to Advance Directives – In case of accident or emergency
Allow doctors to know your wishes and preferences

Explaining common medical situations and decisions patients may need to make.

Audio/video in small screen explaining each step to the user.
Advance Directive – easy steps – Getting started

At each step the audio/video (man in suit) explains what is needed. Selecting your spokesperson is very important and should be selected with great care.
Rating your preferences and values on a scale makes it easier to complete the questions.
Select your answers which best reflect your wishes with regard to your medical treatments. It also explains the treatments by selecting the help button at any time.

You can get information about common medical treatments and select your preferences.
You can get information about common medical conditions and select your preferences. You may not have any these conditions now but you can decide if you do experience any one of them how you would like to be treated.

Dementia – one of our most common medical conditions. You can just read the summary information or select the ‘More Information about Dementia’ button and get more information if you want.
What would most influence you when making your decisions?

Nearly there, ‘Putting it all together’.
Now you have made your decisions, what next?

No point in making decisions if you don’t tell anyone.

At the end, the programme translates all your values and preferences in to an advance directive in the form of a PDF document which you can print out or
send to others. The advance directive is formatted to be understandable to clinical professionals as well as your spokesperson and family and friends. Discuss it with them; amend the advance directive if you want to. This is witnessed and registered where it can be available to healthcare professionals 24/7 whenever it may be needed.
Sample PDF of Advance Directive.
Example – Julius Caesar – generated by Making your Wishes Known

Julius Caesar Advance Directive.pdf
Think Ahead – Sample Form
From the Irish Hospice Foundation.

Think-Ahead-July-2014.pdf
Bibliography

1996b. A Ward of Court (withholding medical treatment) (No 2). The Supreme Court.
1997b. Re MB (Adult, medical treatment).
2001b. Re AK (Medical Treatment: Consent). Family Division, UK.
2003a. HE v a Hospital NHS Trust.
2003b. Mental Health (Care and Treatment) (Scotland) Act. Scotland.
2008. Fitzpatrick v FK (No 2). High Court.
COUNCIL OF EUROPE 2012. Protecting human rights and dignity by taking into account previously expressed wishes of patients. In: PARLIAMENTARY ASSEMBLY (ed.).

146


IRISH COUNCIL FOR BIOETHICS 2007. Is it time for Advance Healthcare Directives?

IRISH HOSPICE FOUNDATION 2004. A nationwide survey of public attitudes and experiences regarding death and dying. Irish Hospice Foundation,


IRISH HOSPICE FOUNDATION 2010. Quality Standards for End of Life Care in Hospitals.


IRISH HOSPICE FOUNDATION 2014b. Think Ahead - Speak for yourself. In: IRISH HOSPICE FOUNDATION (ed.).


NATIONAL RIGHT TO LIFE COMMITTEE 1992. Will to Live. US.


Advance Directive for:

Julius Caesar
11/1/2011

Making Your Wishes Known:
Planning Your Medical Future
APPOINTMENT OF MY HEALTH CARE SPOKESPERSON

MY SPOKESPERSON:
I, Julius Caesar, choose as my Health Care Spokesperson, the following to act for me if I am no longer able to make health care decisions for myself:

Calpurnia, my Beloved Wife
78 Via Gallia
Rome, Greater Roman Empire 00001
111-234-5678(H), (W), 111-222-2345(C)

If I revoke my spokesperson’s authority or if my spokesperson is not willing, able, or reasonably available to make a health-care decision for me, my first substitute spokesperson is:

Octavio, my Adopted Son
614 Via Florentia
Rome, Greater Roman Empire 00002
111-669-6969(H), 111-788-8899(W), (C)

If I revoke the authority of my spokesperson and the first alternate spokesperson, or if neither is willing, able, or reasonably available to make a health-care decision for me, my second substitute is:

Mark Antony, my Military Leader
34 Cleopatra Way
Rome, Greater Roman Empire 00002
111-443-2323(H), 111-898-7766(W), (C)

ADDITIONAL CONSULTANTS:
I would like the following individuals to provide advice and guidance to my spokesperson:

Julia Caesaris Minor, My Little Sister, 111-344-5677
Cleopatra VII, Acquaintance, 849-3872-2323

EXCLUSIONS: I DO NOT want the following individual(s) to represent me:

Marcus Junius Brutus, So-called Friend
Cicero, Senate Opposition
APPOINTMENT OF MY HEALTH CARE SPOKESPERSON

MY SPOKESPERSON’S AUTHORITY:

My spokesperson is authorized to make all health care decisions for me permitted by law, including decisions to provide, withhold, or withdraw artificial nutrition and hydration and all other forms of health care that could keep me alive, and decisions to admit me to a nursing home, assisted living, or other facility, unless I state any limitations below. I understand that authority to make all health care decisions includes decisions that could or would allow my death.

LIMITATIONS, IF ANY:

My spokesperson should never authorize that I be treated with leeches.

The appointment becomes effective when I am unable to make or communicate health care decisions for myself.

MY SIGNATURE:

Sign this form in front of two witnesses who meet the requirements listed on the next page. In addition, some states require that the document be signed in front of a Notary Public.

I, Julius Caesar________________, ask that my family, loved ones, doctors, and other health care providers follow my wishes as communicated by my spokesperson or as otherwise expressed in my advance directive.

______________________________  ________________________________
(SIGNATURE)                (DATE)
APPOINTMENT OF MY HEALTH CARE SPOKESPERSON

WITNESS SIGNATURE:

I, the witness, declare that the person who signed this form is personally known to me, that he or she signed or acknowledged the form in my presence, and that he or she appears to be of sound mind and operating under no duress, fraud, or undue influence.

I also declare that I am over 18 years of age and am NOT any of the following:

- Someone appointed as this person’s health care agent or spokesperson or a successor agent or spokesperson
- This person’s health care provider, including owner or operator of a health care, long-term care, or other residential community care facility serving this person
- An employee or spouse of this person’s health care provider
- Financially responsible for this person’s health care
- An employee of a life or health insurance provider for this person
- Related to this person by blood, marriage, or adoption
- A funeral, crematory, or cemetery representative, and
- To the best of my knowledge, a creditor of this person or entitled to any part of his/her estate under a will or codicil or by operation of law

SIGNATURE OF WITNESS #1

SIGNATURE OF WITNESS #2

PRINTED NAME OF WITNESS #1

PRINTED NAME OF WITNESS #2

ADDRESS

ADDRESS

PHONE

PHONE

NOTARIZATION (OPTIONAL):

STATE OF ______________________ COUNTY OF _______________________

On this _____ day of _________________, 20___, the said _______________________,
came before me personally and, under oath, stated that he or she is the person described in the above document and he or she signed the above document in my presence OR acknowledged that the signature on this document is his or her own. I declare under penalty of perjury that the person whose name is subscribed to this instrument appears to be of sound mind and under no duress, fraud, or undue influence.

_________________________________________  __________________________________________
NOTARY PUBLIC               MY COMMISSION EXPIRES:

Notarization of this document is not required by law in most states. However, if the document is both witnessed and notarized, it is more likely to be honored no matter which state you are in.
MY TREATMENT WISHES

GENERAL WISHES:

3. I cherish my life, so long as my quality of life is acceptable. I want only those medical treatments that are likely to be successful in preserving what I consider a good quality of life. This means that if my quality of life is likely to be poor, I would rather live a shorter period of time than undergo medical treatments that prolong my life.

For me, an unacceptably poor quality of life means:

• I had severe pain most of the time that could not be relieved by medications
• I had discomfort most of the time, such as nausea, diarrhea, or shortness of breath
• I had to live permanently in a nursing home
• I were so debilitated that my care caused a severe burden for my family
• I were so debilitated that the cost of my care caused a severe financial burden on my family
• I could no longer make my own decisions
• I could not think clearly and was confused most of the time
• I could not communicate in a way that could be understood by others
• I could not have meaningful relationships with family or friends

SPECIFIC WISHES:

If I experience a moderate/severe stroke that would significantly improve within a year, I would want the following treatments:

<table>
<thead>
<tr>
<th></th>
<th>I WANT</th>
<th>I DON'T WANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney dialysis for less than one month</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Kidney dialysis for greater than one month</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Cardiopulmonary resuscitation (CPR)</td>
<td></td>
<td>✔️</td>
</tr>
<tr>
<td>Mechanical ventilation for a brief period of time (less than 24 hours)</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Mechanical ventilation for up to a month</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Mechanical ventilation for a long period of time (more than one month)</td>
<td></td>
<td>✔️</td>
</tr>
<tr>
<td>Feeding tube for up to one month</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Feeding tube for a long period of time (more than a month)</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Medicines</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>✔️</td>
<td></td>
</tr>
<tr>
<td>Blood Transfusion</td>
<td>✔️</td>
<td></td>
</tr>
</tbody>
</table>
### MY TREATMENT WISHES

If I experience a moderate/severe stroke that would NOT improve, I would want the following treatments:

<table>
<thead>
<tr>
<th>Treatment</th>
<th>I WANT</th>
<th>I DON'T WANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney dialysis for less than one month</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Kidney dialysis for greater than one month</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Cardiopulmonary resuscitation (CPR)</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Mechanical ventilation for a brief period of time (less than 24 hours)</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Mechanical ventilation for up to a month</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Mechanical ventilation for a long period of time (more than one month)</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Feeding tube for up to one month</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Feeding tube for a long period of time (more than a month)</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Medicines</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Surgery</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Blood Transfusion</td>
<td></td>
<td>✓</td>
</tr>
</tbody>
</table>

If I am in a coma that would resolve within a year, I would want the following treatments:

<table>
<thead>
<tr>
<th>Treatment</th>
<th>I WANT</th>
<th>I DON'T WANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney dialysis for less than one month</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Kidney dialysis for greater than one month</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Cardiopulmonary resuscitation (CPR)</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Mechanical ventilation for a brief period of time (less than 24 hours)</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Mechanical ventilation for up to a month</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Mechanical ventilation for a long period of time (more than one month)</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Feeding tube for up to one month</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Feeding tube for a long period of time (more than a month)</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Medicines</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Surgery</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Blood Transfusion</td>
<td>✓</td>
<td></td>
</tr>
</tbody>
</table>
### MY TREATMENT WISHES

If I would spend the rest of my life in an irreversible coma, I would want the following treatments:

<table>
<thead>
<tr>
<th>Treatment</th>
<th>I WANT</th>
<th>I DON’T WANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney dialysis for less than one month</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Kidney dialysis for greater than one month</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Cardiopulmonary resuscitation (CPR)</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Mechanical ventilation for a brief period of time (less than 24 hours)</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Mechanical ventilation for up to a month</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Mechanical ventilation for a long period of time (more than one month)</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Feeding tube for up to one month</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Feeding tube for a long period of time (more than a month)</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Medicines</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Surgery</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Blood Transfusion</td>
<td></td>
<td>✔</td>
</tr>
</tbody>
</table>

If I develop moderate/severe dementia and am unable to care for myself or remember things clearly, I would want the following treatments:

<table>
<thead>
<tr>
<th>Treatment</th>
<th>I WANT</th>
<th>I DON’T WANT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney dialysis for less than one month</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Kidney dialysis for greater than one month</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Cardiopulmonary resuscitation (CPR)</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Mechanical ventilation for a brief period of time (less than 24 hours)</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Mechanical ventilation for up to a month</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Mechanical ventilation for a long period of time (more than one month)</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Feeding tube for up to one month</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Feeding tube for a long period of time (more than a month)</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Medicines</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Surgery</td>
<td></td>
<td>✔</td>
</tr>
<tr>
<td>Blood Transfusion</td>
<td></td>
<td>✔</td>
</tr>
</tbody>
</table>
MY TREATMENT WISHES

QUALITY OF LIFE:

<table>
<thead>
<tr>
<th>Life would be worth living, but just barely:</th>
</tr>
</thead>
<tbody>
<tr>
<td>- If I had severe pain most of the time</td>
</tr>
<tr>
<td>- If I had discomfort most of the time, such as nausea, diarrhea, or shortness of breath</td>
</tr>
<tr>
<td>- If I had to live permanently in a nursing home</td>
</tr>
<tr>
<td>- If I were so debilitated that my care caused a severe burden for my family</td>
</tr>
<tr>
<td>- If I were so debilitated that the cost of my care caused a severe financial burden on my family</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Life would not be worth living:</th>
</tr>
</thead>
<tbody>
<tr>
<td>- If I could no longer make my own decisions</td>
</tr>
<tr>
<td>- If I could not think clearly and was confused most of the time</td>
</tr>
<tr>
<td>- If I could not communicate in a way that could be understood by others</td>
</tr>
<tr>
<td>- If I could not have meaningful relationships with family or friends</td>
</tr>
</tbody>
</table>

END OF LIFE/issues:

At the end of my life...

...these things are IMPORTANT to me:
- Avoiding pain and suffering, even if it means I might not live as long.
- Being at home when I die.

...these things are EXTREMELY IMPORTANT to me:
- Being kept alive long enough for my family to see me before I die, even if I am unconscious.
- Being alert, even if it means I might be in pain.
# MY TREATMENT WISHES

## ADDITIONAL WISHES:

### PAIN CONTROL:
If I have severe pain, I would want to receive enough medication to relieve my pain only if it would not leave me disoriented or confused most of the time.

### CONFLICTS:
If I am unable to speak for myself and the judgments of my spokesperson conflict with the instructions expressed in my advance directive, I would want my spokesperson’s judgments to override my written instructions.

### RESEARCH PARTICIPATION:
If I am unable to make my own medical decisions, I would want to participate in clinical research that might benefit others or society in general, even if it was unlikely to benefit me personally.

### PREGNANCY:
Not applicable.

### ORGAN DONATION:
I would want to donate any organs or tissues except: eyes

### BODY DONATION:
I would be willing to donate my body for the following purposes:
Research

### DISPOSITION OF MY BODY:
I have no preferences about how my body is disposed of.

### AUTOPSY:
I would want an autopsy if there are questions or concerns about the cause of my death.

### RELIGION & SPIRITUALITY:
I consider myself to have a direct lineage with the Gods of Knowledge and of War, and wish to be regarded and treated accordingly.

### OTHER:
I would like my family to gather at my deathbed so that we may exchange our spiritual farewells.
MY TREATMENT WISHES

MY SIGNATURE:

Sign this form in front of two witnesses who meet the requirements listed on the next page. In addition, some states require that the document be signed in front of a Notary Public.

I, Julius Caesar , ask that my family, loved ones, doctors, and other health care providers follow my wishes as communicated by my spokesperson or as otherwise expressed in my advance directive. These wishes should take effect only if I am unable to make decisions or communicate for myself.

(SIGNATURE)  (DATE)

WITNESS SIGNATURE:

I, the witness, declare that the person who signed this form is personally known to me, that he or she signed or acknowledged the form in my presence, and that he or she appears to be of sound mind and operating under no duress, fraud, or undue influence.

I also declare that I am over 18 years of age and am NOT any of the following:

- Someone appointed as this person’s health care agent or spokesperson or a successor agent or spokesperson
- This person’s health care provider, including owner or operator of a health care, long-term care, or other residential community care facility serving this person
- An employee or spouse of this person’s health care provider
- Financially responsible for this person’s health care
- An employee of a life or health insurance provider for this person
- Related to this person by blood, marriage, or adoption
- A funeral, crematory, or cemetery representative, and
- To the best of my knowledge, a creditor of this person or entitled to any part of his/her estate under a will or codicil or by operation of law

SIGNATURE OF WITNESS #1  SIGNATURE OF WITNESS #2

PRINTED NAME OF WITNESS #1  PRINTED NAME OF WITNESS #2

ADDRESS

ADDRESS

PHONE

PHONE
MY TREATMENT WISHES

NOTARIZATION (OPTIONAL):

STATE OF ______________________, COUNTY OF ______________________

On this ____ day of ________________, 20____, the said ____________________,
came before me personally and, under oath, stated that he or she is the person described in the above document
and he or she signed the above document in my presence OR acknowledged that the signature on this document
is his or her own. I declare under penalty of perjury that the person whose name is subscribed to this instrument
appears to be of sound mind and under no duress, fraud, or undue influence.

______________________________                      ________________________________
NOTARY PUBLIC                               MY COMMISSION EXPIRES:

Notarization of this document is not required by law in most states. However, if the document is both witnessed and
notarized, it is more likely to be honored no matter which state you are in.
MY FORM

Name:

National Council of the Forum on End of Life, 32 Nassau Street, Morrison Chambers, Dublin 2.
THE BENEFITS OF THINKING AHEAD AND THINGS TO CONSIDER

• What if a day comes when you are unable to make decisions for yourself?
• What if you are suddenly taken ill, are involved in an accident or lose your ability to think clearly or independently?
• Do your closest family members or friends really know your wishes?

The purpose of Think Ahead is to guide members of the public in discussing and recording their preferences in the event of emergency, serious illness or death.

The Think Ahead form is a planning document for use by adults who are well. It aims to guide you in thinking about, discussing, and recording your preferences regarding all aspects of end of life.

It encourages you to ensure that those closest to you are aware of these preferences so that, should a time come when you are unable to express them yourself, your wishes will be clear to those caring for you or managing your affairs.

There is no obligation to fill out the complete form; it is entirely voluntary and you should only fill out those sections you are comfortable with. The most important information you can provide includes details about your identity (name, address etc.) and who you would like contacted in the event of an emergency. If you do wish to fill out the entire form, we encourage you not to fill it all out at once. Instead, take your time and complete it over several sittings.

Medical care is a very personal thing. Our preferences are shaped by our individual beliefs and values. Unless you expressly record your care preferences, your family members or clinicians will not know your wishes, and disagreements may occur. YOU can provide guidance by ‘Thinking Ahead’ and Section 2 of this form focuses on your medical care preferences.

Your GP or treating doctor will obviously be central to your care. We encourage you to discuss your care preferences with them. However, in an emergency situation, the doctor treating you may be completely unfamiliar with you, or your care preferences. In those situations, an express record of your wishes can be very useful.

Finally there are many different factors, such as age and illness, that can change your preferences over time. Regular updating of your wishes is important if they are to be useful in the event of a medical emergency or life limiting illness. For that reason, we encourage you to view this form as a living document that can change to reflect your preferences. Therefore, you should review your Think Ahead form either annually, or as often as is appropriate for you.

If you find this form helpful, please tell others about it. If you would like to support the work of Think Ahead, text TA to 50300 to donate €4.

100% of text cost goes to Think Ahead across most network providers. Some providers apply VAT which means a minimum of €3.26 will go to Think Ahead. Service provider LIKECHARITY 014433890
CONTENTS

Section 1. Key Information  

Section 2. Care Preferences  
How would you like to be cared for while you are hospitalised? Are there cultural or religious preferences that you would like health care staff to consider in caring for you?

2.1 Care Preferences  
2.2 Advance Healthcare Directive  
2.3 Emergency Summary Form  

Section 3. Legal  
In this section of the form you can record information regarding your legal affairs. For example your Will and Enduring Power of Attorney.

Section 4. Financial  
In this section, you can record information which will make it easier for your family/legal representative to have details of your finances to assist you when you lack capacity and to arrange your financial affairs after your death.

Section 5. When I Die  
Here you can record your preferences in relation to what happens after you die, i.e. Organ and body donation, Hospital post-mortem, Funeral ceremonies and burial arrangements.

Appendix  

Glossary

Fill out only information you feel comfortable providing. Once you have filled out the form, store it in a safe place. Make sure to tell those closest to you about your wishes, and where to find the form in an emergency.

INFORMATION KEY

Share this Information  
Confidential Financial Information  
In case of Emergency  

June 2014
SECTION 1. KEY INFORMATION
In Case of Emergency (I.C.E)

This section provides key information about you that can be used to inform your treatment and care in case of emergency.

1.1 Personal Information

Name: ____________________________

Common or Nickname: ____________________________

I would prefer to be called by my: ____________________________

First Name: ____________________________ Surname: ____________________________ Common or Nickname: ____________________________

Address: ____________________________

Phone Numbers: ____________________________

Gender: ____________________________

Date of Birth: ____________________________

Place of Birth: ____________________________

PPS No./Universal Health Identifier No*: ____________________________

* Not yet available in Ireland

1.2 Emergency Contacts

Who would you like to be contacted in the event of an emergency?

It is important to name more than one person if possible, in case someone is not contactable. It is very important that you discuss this with these people, letting them know that you are naming them as your emergency contacts.

1. ____________________________

Name: ____________________________ Relationship: ____________________________ Phone: ____________________________

Address: ____________________________

2. ____________________________

Name: ____________________________ Relationship: ____________________________ Phone: ____________________________

Address: ____________________________

3. ____________________________

Name: ____________________________ Relationship: ____________________________ Phone: ____________________________

Address: ____________________________

If at any point you need help completing this form please visit the Think Ahead website: www.thinkahead.ie
1.3 Emergency Information

Please list all known allergies:
(e.g. Wasp sting, penicillin or food)

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Existing conditions:
(e.g. Diabetes, chronic obstructive pulmonary disease (COPD))

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Have you been hospitalised for a serious illness in the last 5 years?

Yes ☐ No ☐

If yes, please list the reason for hospitalisation, date and hospital attended:

Reason for Hospital Visit/Stay:____________________________________________________

Dates From – To: _______________________________________________________________

Hospital/Clinic attended: ________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

1.4 General Practitioner (GP)/Treating Doctor

Name: _______________________________________________________________________

Home/Office Phone: _____________________________________________________________

Address: ____________________________________________________________________

Mobile Phone: _________________________________________________________________

____________________________________________________________________________

Email: _______________________________________________________________________

____________________________________________________________________________
1.5 Health Insurance Information

Do you have a medical card?

Yes ☐ No ☐

General Medical Services (GMS) Number:
(Featured on front of card)

______________________________

Private Health Insurance

Do you have private Insurance?

Yes ☐ No ☐

Name on Policy:

______________________________

Name of Insurance Company:

______________________________

Policy Number:

______________________________

REVIEWS

Signature: ___________________________ Date Reviewed: ___________________________

Signature: ___________________________ Date Reviewed: ___________________________

Signature: ___________________________ Date Reviewed: ___________________________

Signature: ___________________________ Date Reviewed: ___________________________

Signature: ___________________________ Date Reviewed: ___________________________
If you are taking any ongoing medication, you may list those medications below. You might also consider asking your pharmacist to print a record of these on your next visit which you can staple to this page.
SECTION 2. CARE PREFERENCES

This section provides key information about you that can be used to inform your treatment and care in case of emergency.

This information should be shared with: (Please tick all that apply)

- Family
- Loved Ones
- GP, Nurse, Carer
- Other

- How would you like to be cared for if you were ill?
- Who would you like included in discussions about your medical condition or care?
- Are there cultural preferences or religious beliefs that you would like the healthcare staff to consider in caring for you?

These are important questions and can be answered here so that you are given the best possible care and consideration by the staff at a hospital or in another care setting.

This part of the form contains three separate sections.

1. The first deals with your care preferences in the event that you become ill and cannot speak for yourself.

2. The second is an Advance Healthcare Directive. This allows you to set out your preferences about medical treatments you do not want to receive in the future in case you cannot speak for yourself. It also allows you to nominate someone, called a Patient-Designated Healthcare Representative*, who can speak on your behalf. Advance Healthcare Directives are recognized in the courts, and will soon be provided for in Irish legislation. If you have appointed an attorney under an Enduring Power of Attorney to make healthcare decisions on your behalf, it is important to state what authority you have given your attorney.

3. The final section is an emergency summary sheet containing important information. Remove it from the rest of the form and store it in an easily accessible place for use in an emergency situation.

We recommend that you speak to a healthcare professional before completing this section of the form as he or she may be the person best placed to give you the information you need when deciding about the care and treatment you would like.

2.1 Care Preferences Communication/Information

There may be some instances when your medical condition may prevent you from being involved in discussions about your health. You may be unconscious, or you may be conscious but unable to understand such information due to cognitive impairment/confusion or may simply lack capacity to make decisions. With this in mind:

Would you like a relative or friend to be present with you for conversations with the medical team, or at key events in your care?

Yes ☐  No ☐

Need Help?

If at any point you need help completing this form please visit the ThinkAhead website: www.thinkahead.ie

* See Glossary
If yes, please give the name and relationship of that person:

Name: ___________________________  Relationship: ___________________________

Phone: ___________________________  Email: ___________________________

Care Preferences

If it is determined that your condition is deteriorating and is life-limiting, who should talk to any children, or other close family and friends, about the extent of your illness and the possibility of your death?

Please Specify...

Cultural preferences/Religious beliefs

Are there any cultural preferences or religious beliefs or rituals that you would like to be considered as part of your care? If so please list below:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Is there someone from your cultural community or religious community that you would like to be informed if you are seriously ill? If so please give that person’s name and contact details.

Name: ___________________________

Role: ___________________________

Phone: ___________________________

Email: ___________________________
Other wishes

Thinking about the place you would most like to be cared for if you were nearing death.

Please indicate your first preference by putting the number ‘1’ beside that option. Likewise, please put the number ‘2’ beside your second preference, ‘3’ beside your third preference and so on.

• Home
• Hospice
• Hospital
• Nursing Home
• Other (please specify)

You may change your mind over time and you may also find that when the time comes your preferred place of care may not be possible or available.

Is there anything in particular you would or would not like in your final days of life? (e.g. photos, favourite music, rituals, prayers etc.) Please list preferences:

What I would like.

____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________

What I would not like.

____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________

Besides those wishes already expressed, I would like the following requests or preferences to be considered.

____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________

____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________
2.2 My Advance Healthcare Directive

An Advance Healthcare Directive (AHD) is a written statement made by an adult with capacity (the ability to understand and process information in order to make a decision) setting out his/her preferences about medical treatments they do not want to receive in the future, in case a time comes where they lose capacity or cannot speak for themselves. You cannot demand particular treatments in an Advance Healthcare Directive, but you can refuse medical treatment – even if this refusal is considered by some to be unwise, or may result in your death.

Advance Healthcare Directives are recognized in Irish courts. They will soon be provided for in legislation. They are legally binding, which means that if a valid AHD exists, treating doctors are legally bound to follow them. They can be revoked orally or in writing. They can also be altered at any time, but any alteration must be in writing and must be witnessed in the same way as the original. This section is written in light of the draft heads of the legislation which are currently available. It will be amended as appropriate once the legislation has been enacted.

An AHD also allows you to nominate a Patient Designated Healthcare Representative. This is someone who will be allowed to speak for you if you are unable to speak for yourself. They can have as much authority as you decide to give them, up to and including the power to consent to/refuse life-sustaining treatment on your behalf.

There is no obligation to make an Advance Healthcare Directive. It is completely your decision. This section simply provides you with a space to record any preferences you may have in a way which will meet the requirements for a valid Advance Healthcare Directive.

Importantly, an Advance Healthcare Directive will come into effect only if you lose capacity* and are unable to speak for yourself.

Does this Advance Healthcare Directive contain a refusal of life sustaining treatment?

Yes [ ]  No [ ]

Have you created an Enduring Power of Attorney*?

Yes [ ]  No [ ]

If yes, please give contact details for person(s) appointed as attorney(s).


Have you given your attorney authority to make healthcare decisions on your behalf?

Yes [ ]  No [ ]

If yes, have you given your attorney authority to refuse life sustaining treatment on your behalf?

Yes [ ]  No [ ]

* See Glossary
Patient-Physician Partnership

We strongly recommend that you speak to your GP or primary medical professional before completing this section of the form. He or she may be the person best placed to give you the information you need before deciding about the care and treatment you would like.

Patient-Designated Healthcare Representative

This section allows you to appoint a Patient-Designated Healthcare Representative if you wish. This person may be a trusted family member or a close friend, and will be able to speak for you if you are unable to speak for yourself. Therefore it is important to speak to him or her regarding your wishes. You do not have to appoint a representative and can merely set out your wishes in an Advance Healthcare Directive.

If you decide to nominate a representative, they must be over 18 years of age, not someone who is caring for you in return for payment, and not someone who owns or works in a residential or healthcare facility where you are living.

Your Patient-Designated Healthcare Representative

I have given my Patient-Designated Healthcare Representative the following authority:

- [ ] Power to ensure that the wishes I have expressed in this Advance Healthcare Directive are carried out.
- [ ] Power to consent to or refuse medical treatment on my behalf, apart from life-sustaining treatment.
- [ ] Power to consent to or refuse medical treatment on my behalf, up to and including life-sustaining treatment.

Alternate Patient-Designated Healthcare Representative

(Optional - In the event that the person opposite is unavailable)

Note: Currently, if you specify who you want to act on your behalf this will be respected. Legislation which will provide for the formal recognition of your right to appoint a representative is due to be enacted over the coming months. In this section we have used the terminology used in the proposed legislation.)
Please state your directives with respect to life-sustaining treatment and cardiopulmonary resuscitation (CPR) here. These wishes will have an impact if you become unable to take part effectively in decisions regarding your medical treatment.

**Life-Sustaining Treatments**

*LIFE-SUSTAINING TREATMENT* is treatment which replaces, or supports, a bodily function which is not operating properly or failing. Where someone has a treatable condition, life sustaining treatments can be used temporarily until the body can resume its normal function again. However, sometimes the body will never regain that function.

If there is no prospect for my recovery:

- I wish to have whatever life-sustaining treatments that my healthcare professionals may consider necessary and appropriate.
- OR
- I wish to have whatever life-sustaining treatments that my healthcare professionals may consider necessary unless this will require the following treatments, which I do not wish to receive, even if this refusal will result in my death:
  - Being placed on a mechanical ventilator/breathing machine
  - Dialysis
  - Artificial feeding intravenously
  - Artificial feeding through a tube in the nose (nasogastric tube)
  - Artificial feeding through a tube in the abdomen (PEG tube)
- OR
- I do not want life sustaining treatments at all. If life sustaining treatment has commenced, I request that it be discontinued. I understand that this will result in my death.

There may be some life-sustaining treatments which you would not want to receive in any situation. These may include dialysis, being placed on a ventilator, artificial feeding. If you develop an infection, you may decide not to have *intravenous antibiotics* and also, you may decide not to have oral antibiotics. If there are particular life-sustaining treatments which you do not want to receive, please mention these below.

**Cardiopulmonary Resuscitation** *(CPR)*

In order to make decisions regarding resuscitation preferences, it is important to discuss your health with your doctor as some conditions will not benefit from CPR.

Please tick your preference:

It has been explained to me by Dr ____________________________ that I would not benefit from attempted CPR and I understand this.

Therefore:

- I do NOT want CPR. OR
- I would only like CPR attempted if my doctor believes it may be medically beneficial.
Other Preferences

There may be other situations you would find unacceptable in relation to your health. You can give details here. It is important to specify specific treatments you do not want. E.g. If I am diagnosed with terminal cancer, I do not wish to receive chemotherapy.

__________________________________________

__________________________________________

__________________________________________

This form must be signed by you and by 2 witnesses. Both of these people must be over 18, and at least one of them must not be a member of your family and preferably should not be your attorney or patient-designated healthcare representative.

<table>
<thead>
<tr>
<th>Your Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Witness 1 Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Witness 2 Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Your wishes may change over time. For this reason we strongly encourage you to review this part of the form annually or as often as is appropriate for you. Please also remember that if you do make any changes to your Advance Healthcare Directive, these must be witnessed in the same way as the original.

Irrespective of any decisions about CPR and life-sustaining treatment, you will receive basic care*, which will include normal nutrition and hydration as well as care to relieve pain and alleviate any suffering.

* See Glossary

REVIEWs

<table>
<thead>
<tr>
<th>Signature:</th>
<th>Date Reviewed:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Signature:</th>
<th>Date Reviewed:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Signature:</th>
<th>Date Reviewed:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Signature:</th>
<th>Date Reviewed:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
# 2.3 EMERGENCY SUMMARY FORM

This form concerns your preferences for resuscitation and life-sustaining treatment, and is for the attention of paramedics and out of hours providers in case of an emergency.

<table>
<thead>
<tr>
<th>Patient Name:</th>
<th>Date of Birth</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Address:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Emergency contact persons:</th>
<th>Contact phone numbers:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Location of complete Think Ahead Form:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

I have prepared an Advance Healthcare Directive:  
- [ ] Yes  
- [ ] No  

It can be found: ____________________________

I have nominated a Patient-Designated Healthcare Representative:  
- [ ] Yes  
- [ ] No  

Contact details:

I have appointed an attorney to make healthcare decisions:  
- [ ] Yes  
- [ ] No  

Contact details:

<table>
<thead>
<tr>
<th>Diagnosis:</th>
<th>Are you receiving ongoing treatment/medication for this?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
</tr>
</tbody>
</table>

Details:  
Where do you keep your medications?

<table>
<thead>
<tr>
<th>Details:</th>
<th>Where do you keep your medications?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Date Completed: ____________________________  
Date Reviewed: ____________________________
2.3 EMERGENCY SUMMARY FORM

Continued

FOR PARAMEDICS

Resuscitation Preferences;
Please indicate the option(s) most relevant to your present condition.

I understand that I may not benefit from attempted CPR/defibrillation*, Therefore:

☐ I do NOT want CPR/Defibrillation to be attempted even if it will result in my death.

OR

☐ I would like CPR / Defibrillation to be attempted, if it might be medically beneficial.

FOR GPs AND OUT OF HOURS PROVIDERS

Key Treatment Decisions
(Please also see above section on resuscitation preferences)

☐ I would like such life-sustaining treatments that my treating healthcare professionals consider necessary and appropriate.

OR

☐ I do NOT want life-sustaining treatments at all. If life sustaining treatment has started, I request that it be stopped, even though this will result in my death.

Regardless of the preferences expressed above, I understand that in all cases basic care will be provided.

Any other relevant information:

________________________________________________________________________

________________________________________________________________________

This Think Ahead Emergency Summary Form will guide paramedics and out of hours health professionals in making emergency decisions. It has been developed in association with the Pre-Hospital Emergency Care Council (PHECC) and with input from medical practitioners and legal professionals.

This form must be signed by you.

Your Name:

__________________________  Your Signature:

__________________________
SECTION 3. LEGAL

This section of the Think Ahead form provides key information concerning your financial affairs.

This information should be shared with: (Please tick all that apply)

☐ Family ☐ Legal/Accounting ☐ GP, Nurse, Carer ☐ Other

3.1 Legal

Have you made a Will*? (For more information on how to make a will visit www.thinkahead.ie)

Yes ☐ No ☐

Executor* contact details: ____________________________

Is there any family member for whom financial or other provision needs to be made? If so, you should discuss the possibility of creating a trust* for that person with a legal advisor.

__________________________________________________________________________

Have you appointed Guardians for any children under 18? If so, please specify.

Names Contact details.

__________________________________________________________________________

__________________________________________________________________________

Have you appointed an attorney under an Enduring Power of Attorney? (For more information about Enduring Power of Attorney and how it may be useful to you, visit www.thinkahead.ie)

Yes ☐ No ☐

Please name the person(s) appointed as attorney/s:

__________________________________________________________________________

Are there any limitations on the level of authority that you have given your attorney(s)? For instance, are they responsible for just one area of your estate, finances, personal care, healthcare, or for all of your affairs?

☐ Yes, he/she/they have limited authority. Please specify what areas of your affairs they have authority for

☐ No, he/she/they have general authority for my estate, finances personal care and healthcare.

__________________________________________________________________________

Have you given your attorney(s) authority to refuse life-sustaining treatment on your behalf?

Yes ☐ No ☐

It is necessary for a solicitor and medical practitioner to certify that you are freely making an Enduring Power of Attorney and understand the implications of doing so.
## SECTION 4. FINANCIAL

This section of the Think Ahead form provides key information concerning your financial affairs.

This information should be shared with: (Please tick all that apply)

- [ ] Family
- [ ] Legal/Accounting
- [ ] GP, Nurse, Carer
- [ ] Other

It is important to note that information concerning your financial affairs is of a particularly sensitive nature and you may wish to keep this part of the form separate from the rest. It may be useful to consider filing this part of the form with your solicitor or creating an enduring power of attorney for property and financial affairs. This means you can select one person to be authorised to manage your financial affairs should be unable to do so. For more information about this, please [www.thinkahead.ie](http://www.thinkahead.ie)

In order to make it easier for your family/attorney or executors to assist you in the event that you lack capacity, and to arrange your affairs after your death, please provide the following where relevant to you:

### 4.1 Bank Accounts:

<table>
<thead>
<tr>
<th>Name on Account:</th>
<th>Bank:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 4.2 Insurance: (Home, property, car, etc.)

<table>
<thead>
<tr>
<th>Item Insured:</th>
<th>Account Number:</th>
<th>Policy Number:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 4.3 Life Assurance

<table>
<thead>
<tr>
<th>Provider:</th>
<th>Account Number:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If at any point you need help completing this form please visit the Think Ahead website: [www.thinkahead.ie](http://www.thinkahead.ie)
4.4 Credit Cards

Type: 

Name of Financial Institution: 

4.5 Tax Affairs

Details of the Revenue Tax Office/District that deals with your Tax Affairs
(This information is available on your annual certificate of tax credits and other correspondence you receive from the Revenue Commissioner)

4.6 Pensions

Employment/Job related Pension: Reference or Account Number: 

Private/Personal Pension: Name of Pension Scheme/Provider Reference or Account Number: 

Social Welfare Pension: Reference or Account Number: 

4.7 Mortgage Documents/House Deeds:

Property: Location of Documents: 

Note: If your title is registered, you may not have title documents in your possession as details of your title to property may be held by the Property Registration Authority.
4.8 Other Assets/Debts

List other assets (property, shares, etc.) and liabilities (debts) that you may have here.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Other professional(s) that should be contacted with regard to your financial affairs (e.g. accountant, tax consultant, investment advisor etc.)

<table>
<thead>
<tr>
<th>Name:</th>
<th>Role:</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
SECTION 5. WHEN I DIE

This section of the Think Ahead form will allow you to record private and personal wishes for what you would like to happen after you die: Whether or not you would like a post mortem* to be carried out, whether or not you would like to donate your body or organs, where and how you would like to be buried and how you would like to be best remembered.

It will allow you to consider topics, open up conversations that you might otherwise find awkward or difficult or just capture details in one central place.

In this section you can record your preferences in relation to what happens after you die. This can include:

- Organ donation
- Body donation
- Hospital post-mortem
- Funeral ceremonies and burial arrangements

5.1 Organ Donation

Organ donation and transplantation currently saves the lives of between 200 and 250 people in Ireland every year. Each organ and/or tissue donor could save the lives of up to 8 people who are in the end-stage of organ failure.

Organs that are suitable for transplant are the heart, heart valves, kidneys, liver, lungs and pancreas. You may wish to donate all, or some, of these. Only those which have been specifically consented to are taken for transplantation.

Although you may express a preference to become an organ donor, written consent from your next of kin will also be required at the time of a potential donation.

Having a medical condition does not necessarily prevent you from becoming a donor, however this will be decided by a healthcare professional on a case-by-case basis.

The removal of organs is carried out with the same care and respect as any other operation and organ donation does not disfigure the body or change the way it looks. Nor does it cause any delay to funeral arrangements.

Provided they are suitable for donation at the time, I would like to donate the following:

- Kidneys
- Liver
- Heart/lungs
- Pancreas
- All

Other (please specify)

Note: You cannot volunteer to donate your body to medical science if you have already elected to donate your organs. This means that you should not complete both section 5.1 and section 5.2

* See Glossary

If at any point you need help completing this form please visit the Think Ahead website: www.thinkahead.ie
5.2 Body Donation

Medical research is a vital way in which the health profession can learn more about the human body and how to treat illness.

Donating your body for academic purposes in Ireland must be made with one of the following medical educational facilities prior to your death: University College Dublin, Trinity College Dublin, The Royal College of Surgeons in Dublin, University College Cork, University College Galway.

There are some medical conditions that can prevent acceptance as a donor. These include: Hepatitis, HIV and Tuberculosis. Education facilities will not be able to accept a body donation if a post mortem has been carried out. For these reasons, it is also important that you make alternative arrangements in the event that remains are unsuitable for donation.

There is no upper age limit for donation, nor does amputation prohibit the acceptance of a body for medical research.

Bodies that have been donated for medical research are normally released for burial or cremation between 1 and 3 years from the time of death.

If you have made prior arrangements with an education facility to donate your body for the study and research of human anatomy for the advancement of medical science please give details below:

Name of Educational Facility:

Address:

Contact Name .................................................. Contact Number:

5.3 Post-Mortem

A post-mortem is a medical examination carried out on the body after death. It can provide information that may be valuable for your family, your treating doctor, or both.

There are 2 main circumstances in which a post-mortem may be carried out:

1. Where a death is sudden or unexplained, the local Coroner must be informed and he/she may direct that a post-mortem be carried out in the course of the investigation before a death certificate may be issued. Consent of next of kin is not required where a post-mortem is requested by a Coroner.

2. The family of a deceased person, or the deceased person’s doctor, may request that a post-mortem be carried out. This is what is called a hospital post-mortem. Where a doctor has requested a post-mortem, consent of next of kin must be obtained.

If, upon my death, a hospital post-mortem is requested by a healthcare professional, my family should consent to this:

Agree ☐ Disagree ☐
5.4 Funeral and Burial Arrangements

Are there any specific individuals, friends, acquaintances, groups or organisations with which you have been involved that you would like to be notified in the event of your death?

Please include all relevant details such as name, address, telephone number and e-mail address.

_______________________________________________________________________________
_______________________________________________________________________________
_______________________________________________________________________________
_______________________________________________________________________________
_______________________________________________________________________________

Are there any churches, church members or religious organisations you would like to be notified in the event of your death?

Yes ☐ No ☐

Please Specify:

_______________________________________________________________________________

I would like the following person to be responsible for making my funeral arrangements:

Name:

_______________________________________________________________________________

Address:

_______________________________________________________________________________

Phone: Email:

_______________________________________________________________________________

I have made pre-paid funeral arrangements:

Yes ☐ No ☐

If Yes, please give details:

_______________________________________________________________________________
_______________________________________________________________________________
_______________________________________________________________________________
When I die

My preferred funeral director is:

Name: ____________________________________________

Phone: __________________________________________

Address: _________________________________________

Do you own/are you entitled to be buried in a particular grave? If Yes, please give details:

_________________________________________________

_________________________________________________

_________________________________________________

I wish to be: Please Circle

A) Buried

B) Cremated

Preferred cemetery or crematorium:

_________________________________________________

_________________________________________________

_________________________________________________

I would like my ashes to be scattered in the following location(s):

_________________________________________________

_________________________________________________

_________________________________________________

Type of Ceremony:

☐ Civil ☐ Religious

☐ Elements of Both

I wish my funeral ceremony to be held at:

_________________________________________________

_________________________________________________

I would like the following person to be the Celebrant/Master of Ceremonies:

_________________________________________________
Please state, in order of preference, anything in particular you might like in your funeral service or ceremony (e.g. prayers, poems, readings, tribute, words on gravestone, flowers, music, donations to charity, refreshments, etc.). This might help guide your bereaved loved ones at a difficult time. However, also bear in mind that they may not be able to fulfil all of your wishes. For ideas and resources please see the Think Ahead website at [www.thinkahead.ie](http://www.thinkahead.ie).

Please state preferences:

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________
# APPENDIX

## 1. Where to find my important documents

<table>
<thead>
<tr>
<th>Details:</th>
<th>Place Kept:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will/ Trusts</td>
<td></td>
</tr>
<tr>
<td>Insurance Policies</td>
<td></td>
</tr>
<tr>
<td>Pensions</td>
<td></td>
</tr>
<tr>
<td>Bank Accounts</td>
<td></td>
</tr>
<tr>
<td>Credit Cards</td>
<td></td>
</tr>
<tr>
<td>Mortgage Documents/House Deeds</td>
<td></td>
</tr>
<tr>
<td>Birth/Marriage Certificates</td>
<td></td>
</tr>
<tr>
<td>Grave Papers</td>
<td></td>
</tr>
<tr>
<td>Other important documents.</td>
<td></td>
</tr>
</tbody>
</table>

## 2. I have the following social media accounts:

- Facebook [ ]
- Twitter [ ]
- LinkedIn [ ]
- Instagram [ ]
- Google+ [ ]
- Myspace [ ]

Other [ ] Please specify ____________________________

## 3. Subscriptions

I have the following subscriptions/standing orders which should be reviewed

*List below:*

________________________

________________________

________________________

________________________

________________________

________________________

## 4. Pets

I have the following pets that will need to be cared for

*List below:*

________________________

________________________

________________________

________________________

________________________

________________________
**Advance Healthcare Directive**
A written statement made by a person with capacity, setting out his/her will and preferences about medical treatments that may arise in the future, at a time when they no longer have capacity and so cannot make decisions.

**Attorney**
The name given to a person you have given authority to manage your affairs/make healthcare decisions on your behalf in the event that you lack the capacity to make those decisions for yourself.

**Basic Care**
This includes, but is not limited to, warmth, shelter, oral nutrition and oral hydration and hygiene measures.

**Capacity**
The ability to understand the nature and consequences of a decision, in the context of the choices available, at the time the decision has to be made.

**Cardio Pulmonary Resuscitation (CPR)**
An emergency manoeuvre which is applied directly to the chest of a person whose heart has stopped. It manually preserves brain function until further measures can be taken to restore regular blood circulation and breathing.

**Defibrillation**
Treating the heart with a dose of electricity when it has stopped. The device used to do this is called a defibrillator.

**Dialysis**
A process for removing waste and excess water from the blood. It is mainly used as an artificial replacement for kidney function in a person whose own kidneys are failing or have failed.

**Enduring Power of Attorney**
This is a legal document which a person can create while they have capacity, in which they can appoint another person to act on their behalf if a time comes when they no longer have capacity to make decisions.

**Executor(s)**
This is a person(s) named in a Will that will have responsibility for making sure the instructions contained in the Will are carried out.

**Intravenous**
A method of administering medication or fluid to a patient by delivering it directly into their veins.

**Life Assurance**
This is an insurance product where monthly payments are made to an insurance company, in return for which they either make a lump sum payment to your family or meet a particular liability (e.g. mortgage) if you die.

**Life sustaining treatment**
Treatment which replaces, or supports, a bodily function which is not operating properly or failing.

**Nasogastric tube feeding**
A method of artificial feeding in which a tube is passed through the nose, past the throat, and down into the stomach.

**Palliative Care**
An area of healthcare which aims to improve the quality of life of patients through the prevention and relief of suffering. It can be appropriate for patients in all disease stages, from those undergoing treatment for curable illnesses to those nearing end of life.

**Patient-Designated Healthcare Representative**
A person you may choose to nominate in an Advance Healthcare Directive. This person will have authority to speak for you regarding healthcare decisions if you lose capacity and cannot speak for yourself.

**PEG tube feeding**
Percutaneous endoscopic gastrostomy. This is a method of artificial feeding in which a tube is passed into a patient’s stomach.

**Trust**
This is where property is held “on trust” for the benefit of another person. Often, people create trusts in their lifetime or in their Will setting out how money or property should be handled for minor children or other family members who, for some reason, cannot take responsibility for it themselves.

**Ventilator**
A machine which provides a mechanism of breathing for a patient who cannot breathe properly for themselves. It mechanically moves breathable air in and out of the lungs.

**Will**
This is a legal document which sets out in writing your wishes for how your property/possessions should be distributed upon your death.