



THE IRISH COUNCIL FOR

BIOETHICS

COMHAIRLE BITHEITICE NA HÉIREANN

IS IT TIME FOR ADVANCE HEALTHCARE DIRECTIVES?

OPINION

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Is It Time For Advance Healthcare Directives? Opinion

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Preface

The role of the Irish Council for Bioethics (ICB) is to examine the ethical issues raised by developments in science and medicine and to provide information and advice on such issues in order to promote public awareness and understanding. One area where medicine and medical technologies have expanded and developed is in the field of life-sustaining treatment. Advance healthcare directives arose as a means for individuals to control their medical treatment and care in such instances. There have been a number of high-profile cases that have drawn attention to this issue among the general public.

Given the interest in and concern surrounding the topics of end-of-life care and advance healthcare directives in general, and among the Irish public in particular, in addition to the relative uncertainty regarding the status of such directives in Ireland, the ICB decided to undertake a detailed examination of this subject. With this document, the ICB aims to provide a balanced and objective overview of the legal and ethical issues pertaining to the feasibility, format, content and implementation of advance healthcare directives. The document also outlines the Council's opinion and recommendations on some of these issues, particularly from an Irish perspective. It is envisaged that this opinion will facilitate further discussion and debate on the issue of advance healthcare directives and their position in Irish society.

I want to express my appreciation and thanks to the members of the rapporteur group and the Council, as well as to the professional staff of the Council, for the time and effort they expended in the preparation of this document. The Council is also particularly grateful to all those who contributed to the consultation process, as their input was an integral part of the Council's deliberations on this issue.

A handwritten signature in blue ink, appearing to read 'Dermot Gleeson', with a stylized, flowing script.

Dermot Gleeson SC

Chairman

Irish Council for Bioethics

Foreword

The concept of the advance healthcare directive arose in the late 1960s due to a combination of factors. Firstly, people were developing an increased understanding of patient autonomy and the level of decision-making control they had, particularly with regard to refusing or withdrawing medical treatment. Secondly, people began to express more interest in end-of-life care and dying and the treatment they would receive at that time, with many people concerned that their lives might be prolonged indefinitely through the use of unwanted or futile medical treatment. The scope and coverage of advance healthcare directives has expanded greatly since these beginnings and directives no longer cover just medical matters but all aspects of treatment and care.

From an Irish perspective, there appears to be an interest in advance healthcare directives among the general public,¹ despite the lack of either specific legislation or sufficient case law on this subject. Given this interest it is important that society plays a role in resolving any problems and concerns associated with advance healthcare directives and general decision-making for incompetent individuals, particularly those related to end-of-life treatment and care. Considering that the proportion of the population over the age of 65 is expected to rise markedly in the next 15 years,^{2,3} issues relating to end-of-life treatment and care will become ever more relevant. As Ireland's population continues to age and medical technology continues to prolong the natural course of life, individuals and families are destined to face more complex medical decision-making in the future. Society can benefit from a debate on the value, scope and role of advance healthcare directives at the end-of-life.

The Irish Council for Bioethics (ICB) recognises the public's interest in the area of advance healthcare directives and has taken this opportunity to examine the ethical and legal issues pertaining to such directives. The ICB aims, through the publication of this opinion document, to facilitate increased dialogue on this complex topic. The document itself examines a host of issues related to advance healthcare directives that the ICB felt merited particular attention, such as, their legal status in Ireland, the extent and limits of an individual's autonomy, the scope and coverage of advance healthcare directives and their implementation. The document aims to give a balanced overview and discussion of each particular issue considered before the ICB provides its conclusions and recommendations on that issue.

It should be noted that, for the purposes of this document, the ICB concentrated on the issues surrounding advance healthcare directives dealing with end-of-life treatment and care. However, the ICB acknowledges that the use of advance healthcare directives is not confined to end-of-life matters and particular attention should be drawn to two specific areas, namely: advance healthcare directives made by a parent regarding the treatment and care their child might receive in the

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- 1 See Irish Council for Bioethics and TNS MRBI, 2005. *Public Attitudes Towards Bioethics*. Dublin, 49p. Accessed at <http://www.bioethics.ie/work/attitudes.html> and Irish Hospice Foundation, 2004. *A nationwide survey of public attitudes and experiences regarding death and dying*. 56p. Accessed at http://www.hospice-foundation.ie/cfmdocs/pdf/survey_of_attitudes_to_death_and_dying_2005.pdf for more details.
 - 2 Central Statistics Office, 2005a. *Regional Population Projections 2006-2021*. Dublin, Ireland, p.2. Accessed on 10, August 2006 at <http://www.cso.ie/releasespublications/documents/population/current/poppro.pdf>
 - 3 O'Neill, D and O'Keeffe, S 2003. Health Care for Older People in Ireland. *Journal of the American Geriatrics Society* 51: 1280-1286.

future; and also advance healthcare directives made by pregnant women. While many of the issues relating to advance healthcare directives at the end-of-life would also apply to these other categories of advance healthcare directives, both parental directives and those made by pregnant women highlight other issues and raise additional questions that deserve detailed consideration in their own right. These topics have, thus, been excluded from this document but may be examined by the ICB at some time in the future.

In order to inform its decision on the issues relating to advance healthcare directives that deserved consideration in this opinion document, the ICB sought the views of the general public and key stakeholder groups on this topic through a wide consultation process. Appendix 1 contains a detailed analysis of the responses received as part of the public consultation as well as a copy of the questionnaire used during the consultation. The ICB is very grateful to all those individuals who responded during the consultation process and particularly to Dr. Patrick Flanagan for his work on the analysis of these responses. The stakeholder groups contacted were chosen based on the relevance of advance healthcare directives to their particular area of activity and expertise. The list of all stakeholder groups that were contacted as part of the consultation process is given in Appendix 2, while Appendix 3 contains the list of all the stakeholder groups that made a submission to the ICB.

Appendix 4 contains sample advance healthcare directive forms, general value statements and more specific forms allowing for the nomination of a proxy decision-maker. These forms are representative of the types of directives discussed in the document.

The ICB would also like to extend its gratitude to the members of the secretariat, Dr. Siobhán O'Sullivan, Ms. Emily de Grae, Dr. Stephanie Dyke and in particular to Mr. Paul Ivory who were instrumental in the compilation of this document.



Dr. Peter McKenna



Mr. Asim A. Sheikh, BL



Prof. David Smith

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The Origin and Development of Advance Healthcare Directives

An advance healthcare directive is 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 that time. Advance healthcare directives, also variously known as advance directives, instruction directives, advance treatment directives and advance statements, can be oral, written or otherwise recorded. The commonly used term “living will” refers specifically to a written advance healthcare directive. Hereafter, advance healthcare directives will be referred to as advance directives.

The healthcare proxy is a form of advance directive, whereby the author of the directive nominates another person (the proxy) to be involved in the healthcare decision-making process on the author’s behalf should he/she become unable to express his/her wishes. The proxy can make a healthcare decision based solely on his or her judgment of what the author would want in that situation. Alternatively, the proxy could interpret for the members of the healthcare team the author’s wishes regarding healthcare in a given situation, as set out in the advance directive.⁴

Origin of Advance Directives

The concept of the advance directive is a relatively new one, having first originated in the United States (US) in the late 1960s. During the 1950s and 1960s there were a number of advances in medicine, such as, the development of artificial ventilators and cardiopulmonary resuscitation, which offered doctors the possibility of prolonging life in situations where the patient would previously have died.^{5,6} During the same period, a new awareness of patient autonomy saw individuals take more control over their bodies and their medical decisions,⁷ particularly in relation to their right to refuse or withdraw treatment.⁸ In addition, people were developing an increased interest in end-of-life care, which coincided with the beginnings of the hospice movement in the United Kingdom (UK)^{9,10} and the “Right-to-Die” movement in the US.¹¹ The combination of these factors raised concerns about being kept alive indefinitely through unwanted or futile medical treatment.¹² Individuals began to voice concerns about their wishes being respected in such circumstances, and about the emotional and financial burden that such situations could place on their family.¹³ It was already established

4 The President’s Council on Bioethics, 2005. *Taking Care – Ethical Caregiving in Our Aging Society*. Washington, D.C., p.58.

5 Laakkonen, M-L 2005. *Advance Care Planning – Elderly patients’ preferences and practices in long-term care*, PhD Thesis, University of Helsinki, p.15.

6 Brown, BA 2003. The History of Advance Directives. A Literature Review. *Journal of Gerontological Nursing* 29 (9): 4-14.

7 Walter, JJ 2005. Medical Futility – An ethical issue for clinicians and patients. *Practical Bioethics. Clinical and Organizational Ethics* 1 (3): 1, 6-8.

8 Brown, *op. cit.*

9 *ibid.*

10 Laakkonen, *op. cit.*, p.15.

11 *ibid.* p.18.

12 In healthcare terms, futility refers to a medical treatment or procedure that is considered to offer a low probability of success in the current medical circumstances.

13 The President’s Council on Bioethics, *op. cit.*, p.58 and 59.

in US law that adults could refuse medical treatment, even in situations where it could result in their death.^{14,15,16} Such treatment refusals were not possible if an individual was considered, whether through illness or injury, to lack competence.

On the basis of respect for a patient's autonomy, an American lawyer named Luis Kutner proposed the first living will in 1969, in order to facilitate those patients who wished to avoid being kept alive in a "state of indefinite vegetated animation" at some point in the future.¹⁷ The early version of the living will that was proposed comprised a notarised and attested written document, drafted while the individual was mentally competent, stating that the individual did not want to receive further medical treatment should he/she enter an irrecoverable vegetative state. In Kutner's proposal, this living will document would not come into effect unless the individual was in a comatose state, therefore, the living will could be revoked at any time prior to that. In addition, it was suggested that this living will could also include decisions on medical treatment stemming from a person's religious beliefs, such as a Jehovah's Witness refusing blood transfusions or a Christian Scientist refusing all medical treatment. However, it was stated that a request for euthanasia, which was and still remains illegal in the vast majority of states in the US, could not be made in a living will.¹⁸

Development of a Legislative Basis for Advance Directives

Following Kutner's initial proposal, there were a number of unsuccessful attempts¹⁹ to enact legislation on living wills before a bill was finally passed in California in 1976. The *California Natural Death Act* (1976) declared that a competent adult had the right to make decisions regarding life-sustaining treatment, which could include a written instruction to withhold or withdraw such treatment if the patient developed a terminal condition.²⁰

The first judicial support for medical treatment based on an incompetent individual's perceived wishes also occurred in 1976 in the US.^{21,22,23} The case involved a young woman, Ms Karen Ann Quinlan, who was diagnosed in a persistent vegetative state (PVS) and whose family wanted to remove her respirator.²⁴ The New Jersey Supreme Court stated that if Ms Quinlan had been competent she could have refused the respirator. The court declared that even though a patient had become incapacitated he/she still had the right to refuse medical treatment, and in this case Ms

14 Kutner, L. 1969. Due Process of Euthanasia: The Living Will, a Proposal. *Indiana Law Journal* 44: 539-554.

15 Pellegrino, ED 2005. Decisions at the End of Life – The Abuse of the Concept of Futility. *Practical Bioethics. Clinical and Organizational Ethics* 1 (3): 3-6.

16 Brown, *op. cit.*

17 Kutner, *op. cit.*

18 *ibid.*

19 Hecht, MB and Shiel, WC Jr. 2005. *Advance Medical Directives (Living Will, Power of Attorney, and Health Care Proxy)*, p.1 and 2. Accessed April 4, 2006 from <http://www.medicinenet.com/script/main/art.asp?articlekey=7813&pf=3&page=1>

20 The President's Council on Bioethics, *op. cit.*, p.59.

21 Hecht, MB and Shiel, WC Jr. *op. cit.*, p.2.

22 Brown, *op. cit.*

23 The President's Council on Bioethics, *op. cit.*, p.59.

24 *In re Quinlan* [1976] 355 A. 2d. 647.

Quinlan's father, as her guardian, could decide to remove the respirator on her behalf if he believed that was what she would have chosen.²⁵ The court ordered that the respirator be removed, but Ms. Quinlan breathed on her own and lived until 1985 sustained by tube feeding.²⁶

The landmark case involving Ms Nancy Cruzan, a patient in PVS, began in the US in 1983.²⁷ Ms Cruzan's family wanted to withdraw her feeding tube, but because Ms Cruzan did not have any form of advance directive the court refused the request. The court stated that it required "clear and convincing evidence" of Ms Cruzan's wish to forgo life-sustaining treatment to uphold her family's decision. However, further legal action ensued and finally in 1990, after witnesses provided evidence of Ms Cruzan's previous statements relating to her healthcare preferences, the court ordered that her feeding tube be removed and she died.^{28,29} The significance of this case was that the initial court ruling confirmed that individuals' previous wishes regarding their future treatment could be used to direct their current treatment, while also enabling each state in the US to devise their own regulations as to the applicability and validity of the individual's previous wishes.³⁰

During this period other American states began to develop their own legislation relating to advance directives, and in 1983 Pennsylvania became the first state to establish legislation for durable powers of attorney for health care.^{31,32} By 1992 all 50 states in the US had enacted some form of legislative framework relating to advance directives.³³ Although the scope and coverage of this legislation varies between the different states,³⁴ the majority of the states have statutes for both living wills and for a durable power of attorney for healthcare.^{35,36,37}

Despite the development of state legislation throughout the US at this time, a number of professional organisations, such as the American Medical Association and the American Bar Association, had reservations about giving advance directives a legal basis.³⁸ However, further support was given to advance directives at the federal level in the US with the enactment in 1991 of the *Patient Self-Determination Act* (PSDA) (1990). The PSDA requires hospitals and all other healthcare organisations receiving federal funding to inform patients, upon their admission, of their right under state law to make decisions about their medical care, including drawing up an advance directive. In addition, the PSDA requires that if an individual has an advance directive then this

25 The President's Council on Bioethics, *op. cit.*, p.60.

26 Brown, *op. cit.*

27 *Cruzan v. Director Missouri Department of Health* [1990] 497 U.S. 261.

28 Brown, *op. cit.*

29 The President's Council on Bioethics, *op. cit.*, p.61.

30 *ibid.*

31 Brown, *op. cit.*

32 The durable power of attorney for healthcare is a legal document in which a competent individual nominates someone to act as their representative and make medical treatment and healthcare decisions on their behalf should they become incapacitated at some time in the future.

33 Hecht, MB and Shiel, WC Jr. *op. cit.*, p.2.

34 The President's Council on Bioethics, *op. cit.*, p.60.

35 Fagerlin, A and Schneider, CE 2004. Enough: The Failure of the Living Will. *Hastings Center Report* 34 (2): 30-42.

36 Laakkonen, *op. cit.*, p.18.

37 Donnelly, M 2002. *Consent: Bridging the Gap between Doctor and Patient*. Cork University Press, Ireland, p.65.

38 Brown, *op. cit.*

needs to be recorded in that individual's medical record.^{39,40} Furthermore, the PSDA legislates for community and staff education relating to advance directives and also ensures that the presence or absence of an advance directive does not influence the provision of care.⁴¹

Expansion of Advance Directives Internationally

The development of advance directives and their associated legislation outside the US has varied considerably from country to country. For example, in Austria a federal law on advance directives has only recently been enacted;⁴² however, it had been obligatory under the *Austrian Federal Hospital Law* of 1957 to register in an individual's medical record his/her refusal of certain treatments in the event of future incapacity, and these instructions had to be taken into account.⁴³

As previously mentioned, increased interest in end-of-life care in the UK in the late 1950s saw the development of the hospice movement. Despite this early interest in end-of-life issues, the question of advance directives was not really broached until the early 1990s with a number of landmark court cases, namely *Re T (adult: refusal of medical treatment)* [1992];⁴⁴ *Airedale NHS Trust v Bland* (1993);⁴⁵ and *Re C (adult: refusal of medical treatment)* [1994].⁴⁶ These cases dealt specifically with the legality of an individual's previous decisions regarding medical treatment.⁴⁷ This case law was interpreted in such a way that an advance refusal of treatment was legally binding, but an individual could not make a legally binding demand for specific treatments.^{48,49}

In 2005 the *Mental Capacity Act* of England and Wales, specifically legislated for advance decisions to refuse treatment and for lasting powers of attorney covering healthcare decisions.⁵⁰ Under this Act, a valid advance refusal of treatment would be legally binding and the decisions of the person nominated under a lasting power of attorney would carry the same weight as if those decisions had been made by the individual who prepared the power of attorney. The purpose of this act was to clarify legal uncertainties and amend the existing law on substitute and assisted decision-making on behalf of individuals with incapacity.⁵¹ The *Mental Capacity Act* approaches issues surrounding an individual's capacity from a functional and decision-specific viewpoint.⁵²

39 The President's Council on Bioethics, *op. cit.*, p.61.

40 Brown, *op. cit.*

41 *ibid.*

42 Federal Act on Living Wills (Patientenverfügungs-Gesetz - PatVG) 2006. *Federal Law Gazette of the Republic of Austria* 55 (1): 1-3.

43 Georges, J 2005. The benefit of advance directives for persons with dementia. In Meeting the challenges of changing societies *Proceedings of the eighth European Conference of National Ethics Committees (COMETH)*, 25-26 April 2005. Dubrovnik, Croatia. p.154.

44 *Re T (adult: refusal of medical treatment)* [1992] 4 All E.R. 649.

45 *Airedale N.H.S. Trust v Bland* [1993] A.C. 2 W.L.R. 316.

46 *Re C (adult: refusal of medical treatment)* [1994] 1 All E.R. 819.

47 British Medical Association, 2000. *Advance statements about medical treatment – code of practice*. Report of the British Medical Association, London. p.5. Accessed on 12, June 2006 at <http://www.bma.org.uk/ap.nsf/Content/codeofpractice>

48 *ibid.*

49 General Medical Council, 2002. *Withholding and Withdrawing Life-Prolonging Treatments: Good Practice in Decision-making*. London, p.47.

50 *Mental Capacity Act* 2005 Chapter 9. Accessed on 26, January 2006 at: http://www.opsi.gov.uk/acts/acts2005/ukpga_20050009_en.pdf

51 *Mental Capacity Act*, 2005 Chapter 9. Explanatory note, paragraph 4. Accessed on 26, January 2006 at: http://www.opsi.gov.uk/acts/en2005/ukpgaen_20050009_en.pdf

52 Law Reform Commission, 2005. *Consultation Paper on Vulnerable Adults and the Law: Capacity* (LRC CP 37-2005), Dublin, p.49.

Elsewhere in Europe, the concept of the advance directive continues to develop in many jurisdictions.⁵³ Specific legislation relating to advance directives has been in place for some time in a number of countries, for example, Finland (*Act on the Status and Rights of Patients* 1992),⁵⁴ Denmark (*Law on Patients' Legal Status* 1998), and the Netherlands (*Medical Treatment Contracts Act* (WGBO) 1994).⁵⁵ A legislative basis also exists for advance directives in Belgium, Estonia, Georgia, Hungary and Spain.⁵⁶ In addition, legislation has been proposed in both Luxembourg and Switzerland, which will cover the status and use of advance directives, while the German parliament is currently in the process of drafting legislation relating to advance directives.⁵⁷

The European Convention on Human Rights and Biomedicine, 1997, also makes reference to advance directives under Article 9, which states that “the previously expressed wishes relating to a 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”.⁵⁸ As of January 2007, twenty European member states, *not* including Ireland, have ratified the Convention.⁵⁹ However, this does not mean that there is a legal endorsement for advance directives in these jurisdictions. In some countries, the legal basis of advance directives may be indirectly based on constitutional or case law. These differences do not imply that advance directives in these countries are less binding.⁶⁰

The concept and awareness of patient autonomy, in terms of controlling medical treatment and care, particularly at the end-of-life, has evolved since the 1950s and 1960s. Advance directives were developed as a result of this increased interest in patient autonomy, and specific legislation for advance directives was initially enacted in the US. More recently, numerous European countries have also established a legal basis for advance directives.

53 Laakkonen, *op. cit.*, p.18.

54 *ibid.* p.17.

55 Alzheimer Europe, 2005a. *Advance directives: Summary of the legal provisions relating to advance directives per country*. p.8 and 27. Accessed on 13, February 2006 at <http://www.alzheimer-europe.org/upload/SPTUNFUYGGOM/downloads/DFE2416EE567.pdf>

56 *ibid.* p.7,10,15,21 and 30.

57 *ibid.* p.2 and 17.

58 Council of Europe, 1997. *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*. Oviedo. Accessed on 30, January 2006 at: <http://conventions.coe.int/Treaty/EN/Treaties/Html/164.htm>

59 For the full list of signatory countries see: <http://conventions.coe.int/Treaty/Commun/ChercheSig.asp?NT=164&CM=1&DF=01/29/2007&CL=ENG>

60 Georges, *op. cit.*, p.154.

The Legal Status of Advance Directives in Ireland

Legal Status of Advance Directives

In Ireland, there is no specific legislation in relation to advance directives. The lack of legislation makes the status of advance directives unclear and, as a result, their implementation may or may not be enforced.^{61,62} Nonetheless, it has been suggested by the Law Reform Commission of Ireland (LRC) that it should be possible for an individual to make a legally binding advance directive, provided the decisions within the directive are themselves legal.⁶³ However, in its final report on the issue of healthcare decision-making for vulnerable adults, the LRC concentrated on “the limited context of certain healthcare decisions which might be conferred using an enduring power of attorney”, as opposed to dealing with the issue of advance directives directly.⁶⁴ It should also be noted that the discussion of the issues surrounding advance directives and end-of-life care has been a relatively recent development in Ireland.⁶⁵ The lack of clarity surrounding the validity and applicability of advance directives in Ireland is, no doubt, a result of the fact that there have been very few decisions of the courts that have touched on the issue of a patient’s previous wishes regarding treatment.

The most relevant case law on this matter comes from *In the matter of a Ward of Court (withholding medical treatment)* [1996], which will hereafter be referred to as the *Ward of Court* case.⁶⁶ This case involved a woman, who had been made a ward of court,⁶⁷ who had been in a near-persistent vegetative state for almost 23 years and whose family wanted to withdraw the artificial nutrition and hydration (ANH), that was sustaining her. The family’s claim was that the ANH treatment was no longer benefiting the woman. The decision of the High Court was to authorise the withdrawal of ANH from the woman and to 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”.⁶⁸ This decision was appealed to the Supreme Court by the healthcare institution caring for the woman, the Attorney General and the guardian *ad litem*. The Supreme Court upheld the original ruling and it was agreed that the woman’s feeding tube should be removed. The Supreme Court’s agreement to the removal of the feeding tube was based on what it considered to be in the woman’s best interests. Since the young woman had not previously expressed any wishes regarding her medical treatment in the event of being in a persistent vegetative state, the court could not

61 Donnelly, *op. cit.*, p.66.

62 Comhairle, 2005. *Relate* 32 (11): 1-8. Accessed on 1, February 2006 at <http://www.comhairle.ie/publications/relate/aug2005.pdf>

63 Law Reform Commission, 2003. *Consultation Paper on Law and the Elderly* (LRC CP 23–2003), Dublin, p.83 and p.84.

64 Law Reform Commission, 2006. *Report – Vulnerable Adults and the Law*. (LRC 83-2006), Dublin, p.87.

65 Campbell, E 2006. The Case for Living Wills in Ireland. *Medico-Legal Journal of Ireland*, 12 (1): 2-18.

66 *In the matter of a Ward of Court (withholding medical treatment)* (No. 2) [1996] 2 IR 79.

67 A ward of court is an individual who, by reason of incapacity, through minority or mental illness, is under the protection of a court either directly or through a guardian appointed by the court. The court has the final authority to make any decisions, medical or otherwise, on behalf of such an individual.

68 *In the matter of a Ward of Court*, *op. cit.*. Mr. Justice Lynch p.99.

claim it had evidence of her wishes regarding treatment.⁶⁹ Thus, the “best interests” criterion was applied. In a statement, Mr. Justice O’Flaherty noted that the idea of substituted judgement⁷⁰ was not relevant in the *Ward of Court* case and suggested that it may only be “appropriate where the person has had the foresight to provide for future eventualities”.⁷¹ Against the backdrop of the *Ward of Court* case, the LRC had previously suggested that, “where a clear preference of the incapacitated person is established, the court will enforce that choice”.⁷² In fact, in its final report examining issues surrounding vulnerable adults and the law, the LRC recommended that where an individual’s past wishes are ascertainable, they should be taken into account during any decision taken on an individual’s behalf.⁷³ Others, such as the Medical Council of Ireland, have suggested that if an advance directive was clear and specific then the treatment preferences outlined in it would be acted on when making a decision on behalf of a person lacking legal capacity.^{74,75}

During the *Ward of Court* case it was emphasised by Mr. Justice Hamilton that, individuals had the right to refuse medical treatment, which stemmed from their personal rights of self-determination, bodily integrity and privacy under the Constitution of Ireland.⁷⁶ The rights of self-determination, bodily integrity and privacy, although unenumerated (*i.e.* not specifically stated), are enshrined in principle in the Constitution of Ireland (1937) under Articles 40.3.1° and 40.3.2°. Article 40.3.1° provides that: “The State guarantees in its laws to respect, and, as far as practicable, by its laws to defend and vindicate the personal rights of the citizen”; and Article 40.3.2° provides that: “The State shall, in particular, by its laws protect as best it may from unjust attack and, in the case of injustice done, vindicate the life, person, good name, and property rights of every citizen.”

Rights in Contemporaneous Healthcare Decision-Making

Heretofore, an individual’s right to self-determination in contemporaneous medical decision-making has not been in question. However, a recent High Court case in Ireland involving an adult Jehovah’s Witness (named Ms. K) has created some uncertainty around this matter.⁷⁷ Ms. K suffered severe blood loss due to complications following the birth of her son and was advised that she needed a blood transfusion and other associated medical treatment. However, as Ms. K was a Jehovah’s Witness she refused to accept the transfusion for personal and religious reasons, despite the likelihood that she would die without it. The hospital involved applied to the court to authorise the required treatment. Nonetheless, while acknowledging that Ms. K was competent, Mr. Justice Abbott stated that the court should intervene to protect both her life and the life and welfare of her son. Mr. Justice Abbott ordered the hospital to give Ms. K the blood transfusion, even though it was

69 *ibid.* Mr. Justice Hamilton p.127, and Mrs. Justice Denham p.168.

70 Substituted judgement involves determining what treatment decisions an incompetent individual would make in their current situation if they were capable of deciding for themselves at that time.

71 *In the matter of a Ward of Court, op. cit.*, Mr. Justice O’Flaherty p.133.

72 Law Reform Commission, 2003, *op. cit.* p.86.

73 Law Reform Commission 2006, *op. cit.* p.74.

74 Medical Council of Ireland, 2006. *Discussion document on Advance Directives*. Accessed on 3, October at www.medicalcouncil.ie/news/discussionarticle.asp?NID=158&T=N

75 Campbell *op. cit.*

76 *In the matter of a Ward of Court, op. cit.*, Mr. Justice Hamilton p.124-126.

77 Sheikh, AA 2006. Medico-Legal Issues and Patient Autonomy – Here Yesterday Gone Tomorrow? *Medico-Legal Journal of Ireland* 12 (2): 2-4.

against her expressed wishes.^{78, 79, 80} Prior to this case it had been recognised that a competent adult individual above 18 years of age had the right to consent to or refuse medical treatment.⁸¹ The situation regarding healthcare decision-making by children and young adults is somewhat different. Under Section 23(1) of the *Non-Fatal Offences Against the Person Act* (1997), an individual who has attained the age of 16 can consent to “any surgical, medical or dental treatment”.⁸² However, it has been noted that section 23(1) of the Act is unclear with regard to the legal standing of a refusal of treatment by an individual aged over 16 years but under 18 years of age.⁸³

A judgement by the Court of Appeal in the UK in relation to refusals of treatment by a minor in the case of *Re W (a minor) (medical treatment)* [1992] found that no minor of any age has power, by refusing treatment, to override a consent given by the court or by a person having parental responsibility. The adolescent’s level of competence is relevant in assessing the weight to be given to his or her views, but these views will not determine the issue.⁸⁴ The paramount consideration is the welfare of the child. The question therefore arises whether an advance directive prepared by an individual who is aged over 16 but less than 18 years of age would be considered legally binding. While individuals aged over 16 but less than 18 years of age are often regarded as being both independent and mature, they are not considered to be fully autonomous by the State as they have not reached the age of majority. Consequently, an advance directive prepared by an individual aged over 16 but less than 18 years of age is less likely to be considered valid and legally binding than one prepared by an individual over 18 years of age.

Notwithstanding the legal issue, the question remains of whether 16-18 year old adolescents should be considered morally autonomous and thus should be permitted to make significant healthcare decisions for themselves. The United Nations Convention on the Rights of the Child (UNCRC) acknowledges the rights of young people, in accordance with their age and maturity, to make their own decisions on matters affecting their lives.⁸⁵ The ability to make autonomous choices depends on the development of cognitive capabilities, such as comprehension, appreciation of consequences, hypothesising alternatives and assessment of benefits and burdens. There is a broad consensus amongst paediatric health professionals and developmental psychologists that adolescents over 15 years of age have the cognitive capacity to make binding medical decisions, including those relating to the discontinuance of life-sustaining measures.^{86,87,88} It has, however,

78 Additional legal proceedings are currently underway between Ms. K and the Coombe Hospital.

79 Managh, R 2006. “Judge orders hospital to give transfusion”. *The Irish Times*, 22nd September 2006. p.8.

80 Donnellan, E 2006. “Woman in court transfusion case recovering in hospital”. *The Irish Times*, 22nd September 2006. p.1.

81 Sheikh, *op. cit.*

82 Section 23(1) states that: “The consent of a minor who has attained the age of 16 years to any surgical, medical or dental treatment which, in the absence of consent, would constitute a trespass to his or her person, shall be as effective as it would be if he or she were of full age; and where a minor has by virtue of this section given an effective consent to any treatment it shall not be necessary to obtain any consent for it from his or her parent or guardian.” Accessed on 25, October 2006 at: <http://www.irishstatutebook.ie/ZZA26Y1997.html>

83 Donnelly, *op. cit.*, p.48.

84 *Re W (a minor)(medical treatment)* [1992] 4 All E.R. 627.

85 Office of the High Commissioner for Human Rights, 1990. *Convention on the Rights of the Child*. Accessed on 14, December 2006 at: <http://www.unhchr.ch/html/menu3/b/k2crc.htm>

86 Weir, RF and Peters C 1997. Affirming the decisions adolescents make about life and death. *Hastings Centre Report* 27: 29-40.

87 American Academy of Pediatrics, Committee on Bioethics, 1995. Guidelines on forgoing life-sustaining medical treatment. *Pediatrics* 95: 314-317.

88 Kuther, TL 2003. Medical decision-making minors: issues of consent and assent. *Adolescence* 38 (150): 343-357.

been suggested that “cognitive maturation also needs to be balanced with the insights that life experience contribute to personal-risk assessment”.⁸⁹ Even when full decisional authority is not appropriate, moral arguments exist for taking account of 16-18 year olds’ treatment preferences.

Any treatment carried out without the consent of patients violates their rights to bodily integrity and privacy⁹⁰ and is considered both trespass and battery.^{91,92} While the right of self-determination ordinarily prevents a third party from consenting to or refusing medical treatment on the patient’s behalf, there are a number of instances where this right can be overridden. For example in emergency situations, where the patient cannot give consent, doctors have the authority to “provide treatment that is necessary to safeguard the patient’s life or health”.⁹³ Following the ruling from the *Ward of Court* case, the right to self-determination was effectively extended to entitle an individual to have a natural death⁹⁴ following the refusal or removal of treatment.⁹⁵ It should be noted, however, that this is not considered a right to die by artificial means nor through the actions of a third party.^{96,97} Therefore, the right to self-determination, while highly regarded, is not absolute, and an individual cannot legally consent to or be assisted in their death by another party.^{98,99}

The weight of legal opinion in the Republic of Ireland recognises the right of competent adults to decide on the nature of their medical treatment. Refusal of treatment by a competent individual to facilitate a natural death is permitted, but this right does not extend to allow euthanasia or assisted suicide.

89 Sanci, LA, Sawyer, SM, Weller, PJ, Bond, LM and Patton, GC 2004. Youth health research ethics: time for a mature-minor clause? *Medical Journal of Australia* 180 (7): 336-338.

90 Ryan, FW 2002. *Constitutional Law*. Round Hall Ltd., Dublin, p.110.

91 *In the matter of a Ward of Court, op. cit.*, Mrs. Justice Denham p.156.

92 *Airedale N.H.S. Trust v Bland* [1993] A.C. 2 W.L.R. 316, Lord Keith p. 360; Lord Browne-Wilkinson p.384, 385; and Lord Mustill p.392.

93 Medical Council of Ireland, 2004. *Guide to Ethical Conduct and Behaviour*, 6th ed. p. 32.

94 A natural death is when the death of an individual results from the normal progress of a disease or illness. Any medical treatment received at this juncture would be palliative rather than curative.

95 *In the matter of a Ward of Court, op. cit.*, Mr. Justice Hamilton p.124.

96 Ryan, *op. cit.*, p. 111.

97 Donnelly, *op. cit.*, p.19.

98 German National Ethics Council, 2005. *The Advance Directive: Opinion*. Berlin, p.44.

99 This is the case everywhere apart from in a small number of states around the world, namely, the Netherlands, Belgium, Switzerland and Oregon in the United States, where euthanasia or assisted suicide have been legalised.

Substituted and Assisted Decision-Making for Incapacitated Adults

The right to self-determination is regarded as an integral part of human dignity and freedom, which should apply equally to all, whether they are healthy or not.¹⁰⁰ The issue of the rights of an incompetent individual was also expanded upon in the *Ward of Court* case, where it was considered by both Mr. Justice Hamilton and Mrs. Justice Denham, that an individual's loss of capacity did not result in any limitation of personal rights under Article 40.1 of the Constitution.^{101,102} Despite acknowledging that everyone, whether competent or not, should have the same rights, problems can arise in situations where an individual is incapacitated and is unable to decide on his or her treatment. The advance directive¹⁰³ was developed for use in exactly these types of situations but, as mentioned previously, the status of advance directives in Ireland is still somewhat unclear. Therefore, it would appear that for the time being in Ireland, the final authority to make decisions on medical treatment on behalf of incapacitated adults rests with the court,¹⁰⁴ under the *parens patriae* jurisdiction, whereby the court decides in the individual's best interests.¹⁰⁵

The *parens patriae* jurisdiction was invoked in the *Ward of Court* case and also in the only other Irish legal case that considers an individual's previous wishes regarding medical treatment, namely, *J.M. v The Board of Management of St. Vincent's Hospital* [2002].¹⁰⁶ This case involved a critically ill woman who required an immediate blood transfusion and liver transplant. The woman had initially refused the blood transfusion for religious reasons¹⁰⁷ but subsequently indicated she would accept the treatment before again appearing to refuse treatment. However, due to the deterioration of the woman's condition, there was confusion over her final decision and she was no longer considered competent to decide for herself. As a result the woman was made a ward of court, and the court decided that the treatment should be provided on the grounds that this was what the woman would choose for herself if she were still competent.¹⁰⁸ It is clear that the *parens patriae* jurisdiction was only invoked in this case because the previous decisions the woman had made regarding her treatment were not considered to be final and definitive.¹⁰⁹

Notwithstanding the rulings in both the *Ward of Court* and the *J.M. v The Board of Management of St. Vincent's Hospital* cases, this small body of case law dealing with advance directives and an individual's prior wishes regarding treatment highlights the need to debate the issue of providing specific legislation relating to advance directives. However, the reliance on the courts to develop

100 German National Ethics Council, *op. cit.*, p.42.

101 *In the matter of a Ward of Court*, *op. cit.*, Mr. Justice Hamilton p.126 and Mrs. Justice Denham p.159.

102 Article 40.1 of the Constitution of Ireland provides that: "All citizens shall, as human persons, be held equal before the law. This shall not be held to mean that the State shall not in its enactments have due regard to differences of capacity, physical and moral, and social information."

103 Unlike in Ireland, other countries may offer both advance directives and durable powers of attorney as a means of medical decision-making for incapacitated adults.

104 Section 9, *Courts (Supplemental Provisions) Act*, 1961.

105 Donnelly, *op. cit.*, p.59.

106 *J.M. v The Board of Management of St. Vincent's Hospital* [2002] 1 IR 321.

107 The woman was married to a Jehovah's Witness and as part of her culture she had adopted his religion.

108 *J.M. v The Board of Management of St. Vincent's Hospital*, *op. cit.*, Mr. Justice Finnegan p.325.

109 *ibid.*

appropriate solutions to these issues is problematic.¹¹⁰ Rather than wait for a body of law to develop on such issues through the courts, it has been proposed that, ideally, it should be society that resolves the moral, social and legal issues surrounding advance directives and end-of-life care.^{111,112}

The LRC, while not directly focusing on the issues of advance directives, has examined certain aspects of the law in relation to substitute and assisted decision-making for vulnerable adults and the elderly. The intention of the LRC is to establish a new Guardianship system to replace the current Wardship system, and at the same time to amend and expand the existing law on enduring powers of attorney (the *Powers of Attorney Act* [1996]).¹¹³ As part of these amendments, the LRC has recommended that both representatives nominated by enduring powers of attorney¹¹⁴ and personal guardians, nominated under the Guardianship system, should be given additional, though limited, medical decision-making authority for minor and routine medical treatment and care.^{115,116} However, under this system the LRC has also recommended that “certain major healthcare decisions such as non-therapeutic sterilisation, the withdrawal of artificial life-sustaining treatment and organ donation should be specifically reserved for the High Court”.¹¹⁷ Furthermore, under this new system a Guardianship Board would be established to appoint personal guardians where it is deemed necessary.¹¹⁸ The LRC considered the High Court to be the final appeal body for any decisions made by the Guardianship Board.¹¹⁹ In addition, a Public Guardian Office would be established to supervise and provide guidance and assistance to the nominated substitute decision-makers, *i.e.* the personal guardian or those named in an enduring power of attorney, while at the same time raising awareness among the general public of capacity issues.¹²⁰

Nevertheless, until these proposed amendments are put in place, the Wardship system will remain in use for incompetent individuals. The Wardship system of decision-making for incompetent individuals is considered inadequate and awkward^{121,122} and is not widely used.¹²³ Consequently, most incompetent people in Ireland do not have a legally recognised representative to act on their behalf.¹²⁴ It is clear, however, that decisions on medical treatment are being made for incompetent individuals, but it is difficult to ascertain how much input such incompetent individuals have in this process. In practice, these decisions are made by members of the medical profession following

110 Hanafin, P 2000. Legislating the Right to Die: Perspectives and Prescriptions, in K Kearon and F O’Ferrall (eds.) *Medical Ethics and the Future of Healthcare*. The Columba Press, Dublin p.139.

111 *ibid.*

112 *Airedale N.H.S. Trust v Bland*, *op. cit.*, Lord Browne-Wilkinson p.382.

113 See the following paper by the Law Reform Commission for more details: *Report – Vulnerable Adults and the Law*. (LRC 83-2006).

114 An enduring power of attorney is a legal document in which a competent individual nominates someone to make certain personal care decisions on their behalf should they become incapacitated at some time in the future.

115 Law Reform Commission, 2006, *op. cit.*, p.106-107 and p.140.

116 A more detailed description of what constitutes minor and routine medical treatment is given in the following papers: Law Reform Commission, 2003, *op. cit.*, p.182-184 and Law Reform Commission, 2005, *op. cit.*, p.208-209.

117 Law Reform Commission, 2006, *op. cit.*, p.144.

118 *ibid.* p.138.

119 *ibid.* p.144.

120 *ibid.* p.150-151.

121 Donnelly, *op. cit.*, p.59.

122 Law Reform Commission, 2006, *op. cit.*, p.114-115.

123 For a more detailed discussion of the Wardship system in Ireland see: O’Neill, A-M 2004. *Wards of Court in Ireland*. First Law, Dublin. 350p.

124 Donnelly, *op. cit.*, p.59.

consultation with the incompetent individual's family or legal guardians. Questions have been raised regarding the legality of this decision-making process,^{125,126} though the courts have suggested it is standard practice in the case of incompetent individuals who are not wards of court.¹²⁷

Nonetheless, discussions involving medical professionals and those close to the incompetent individual do not always reach consensus, and in this context advance directives could facilitate agreement, while at the same time respecting an individual's right to self-determination. Indeed, in the *Ward of Court* case it was suggested by Mr. Justice O'Flaherty that increased publicity of similar cases in the courts would lead to an increase in the number of people "providing for future eventualities" in terms of their medical treatment.¹²⁸ Any increase in the instances of individuals drafting instructions on medical treatment in advance would seem to support the need for specific legislation in this area.¹²⁹

Although the majority of the relevant Irish case law respects an individual's right to self-determination in healthcare decision-making, it remains somewhat uncertain whether an advance directive has any definitive legal standing in the Republic of Ireland. The Wardship system is the currently recognised legal mechanism for healthcare decision-making on behalf of incapacitated adults in the Republic of Ireland. However, this system is in the main considered to be cumbersome and is not often utilised.

125 *ibid.* p.60.

126 Comhairle, *op. cit.*, p.10.

127 *In the matter of a Ward of Court, op. cit.*, Mrs. Justice Denham p.153.

128 *ibid.* Mr. Justice O'Flaherty p.133.

129 Campbell *op. cit.*

The Ethical Framework for Advance Directives

The principle of autonomy refers to an individual's right to think and act as he or she wishes, free from any external influences. Ordinarily this right is recognised and respected, provided the wishes of the individual do not inflict harm on others. This interpretation of autonomy is a reflection of John Stuart Mill's "liberty principle", which states that, "the only part of the conduct of any one, for which he/she is accountable to society, is that which concerns others. In the part that merely concerns himself/herself, their independence is, of right, absolute. Over himself, over his body and mind, the individual is sovereign".¹³⁰ When applied to healthcare situations, the principle of autonomy refers to an individual's right to decide for themselves with regard to their treatment and care. People seeking to express greater autonomy and control over their end-of-life care and, ultimately, the manner of their death, originally devised the concept of the advance directive. However, it took the intervention of court rulings for the original concept to become a reality, through the implementation of specific legislation and regulations.¹³¹

Advance Directives: An Expression of Self-Determination?

One of the key questions to be addressed with regard to advance directives is: does an individual have the right to make an advance directive? It has been argued that the right to an advance directive is an entitlement that stems from, and is a continuation of, an individual's basic human rights of self-determination (autonomy), bodily integrity, privacy and dignity.^{132,133,134} The right of competent adults to make an advance directive, if they wish, is recognised through a number of international agreements.¹³⁵ In addition, specific countries have copper-fastened this right in law by legalising advance directives.¹³⁶ As already noted, competent individuals can consent to or refuse medical treatment and ordinarily, apart from extenuating circumstances such as emergency situations, they cannot be treated without their consent. While recognising the authority of doctors

¹³⁰ Mill, JS 1859. *On Liberty*. Longman, Roberts and Green, London.

¹³¹ See the section entitled "The Origin and Development of Advance Healthcare Directives" for more details.

¹³² German National Ethics Council, 2005. *op. cit.*, p.42-44.

¹³³ Campbell, *op. cit.*

¹³⁴ For a more detailed description of an individual's rights regarding healthcare see: Council of Europe, 1997, *op. cit.*; Active Citizenship Network, 2002. *European Charter of Patients' Rights*, Rome. Accessed on 9, February 2006 at: http://www.activecitizenship.net/health/european_charter.pdf; World Medical Association, 1981-2005. *World Medical Association Declaration on the Rights of the Patient*. Accessed on 26, January 2006 at: <http://www.wma.net/e/policy/l4.htm>

¹³⁵ For example see the Council of Europe, 1997, *op. cit.*, and World Medical Association, 2003. *The World Medical Association Statement on Advance Directives ("Living Wills")*. Helsinki. Accessed on 26, January 2006 at: <http://www.wma.net/e/policy/w14.htm>

¹³⁶ See the section entitled "The Origin and Development of Advance Healthcare Directives" for details of some countries that have legislation regarding advance directives.

to act in such emergency situations, a number of countries respect the previous treatment wishes of the patient, providing these wishes can be identified without undue delays in providing necessary medical treatment.^{137,138,139}

The advance directive has been recognised as an expression of an individual's autonomy and as a useful tool in enabling the individual to maintain some level of control over medical treatment into the future, when he or she might lack the capacity to express autonomous preferences.^{140,141,142} If the wishes of an individual as outlined in an advance directive are not respected, this would enable others to superimpose their own treatment decisions on an individual, at a time when it would be difficult for this now incompetent adult to effectively oppose such decisions.¹⁴³ The rights to bodily integrity and privacy lend support to a moral emphasis on an individual's autonomy in medical decision-making. Treating patients without their consent would breach these rights,¹⁴⁴ thus, violating their dignity and displaying a lack of respect for the wishes of the individual. It should be noted, however, that individuals could also express their right to autonomy by deciding not to make an advance directive. An individual should not be obliged to prepare an advance directive, for example, to avail of medical treatment or to gain admission to a nursing home, as such an obligation could be seen as a breach of autonomy.^{145,146}

Upholding the treatment preferences of the individual respects his or her rights of bodily integrity and privacy and recognises the right to a dignified death. The attitudes, values and perceptions that individuals have surrounding their death, as the final part of their life, are profoundly personal and significant. These values are a reflection of each person's larger philosophy of life. In such cases, not respecting an individual's end-of-life treatment preferences in an advance directive would deprive that individual of the chance to fulfil this philosophy.¹⁴⁷ In many cases, individuals would prefer, where possible, a dignified natural death as opposed to having their life sustained by unwanted medical means, thus enabling them to die "peacefully and with the greatest dignity and least distress".¹⁴⁸ This interest in the manner of death, particularly the concept of a good death, is deeply rooted in Irish society.¹⁴⁹ As outlined earlier, such interest in controlling end-of-life care was foremost in the original evolution of advance directives. An individual's attitude regarding death can also be strongly influenced by his or her personal values, but also by any religious or spiritual beliefs he or she might hold. The ability to use the advance directive to express such religious values and beliefs

137 German National Ethics Council, *op. cit.*, p.47.

138 Italian National Bioethics Committee, 2003. *Advance Treatment Directives*, Rome, p.4.

139 World Medical Association, 1981- 2005, *op. cit.*

140 Scottish Council on Human Bioethics 2006a. *Position Statement: Advance Directives*. Accessed at www.schb.org.uk

141 German National Ethics Council, *op. cit.*, p.44.

142 The President's Council on Bioethics, *op. cit.*, p.68.

143 German National Ethics Council, *op. cit.*, p.51.

144 Ryan, *op. cit.*, p.110.

145 German National Ethics Council, *op. cit.*, p.60, 61.

146 Bachinger, G 2006. Patienten helfen – The New Federal Act on Living Wills in Austria. *NÖ Edition Patientenrechte*, p.12.

147 German National Ethics Council, *op. cit.*, p.51.

148 *Airedale N.H.S. Trust v Bland*, *op. cit.*, Sir Stephen Brown p.331.

149 Keegan, O, McGee, H, Brady, T, Kunin, H, Hogan, M, O'Brien, S and O'Siorain, L 1999. *Care for the dying – experiences and challenges: A study of quality of health service care during the last year of life of patients at Saint James's Hospital, Dublin, from their relatives' perspective*. Irish Hospice Foundation, Dublin. 84p.

with regards to medical treatment was also acknowledged when the idea of the advance directive was first proposed.¹⁵⁰

The Irish Council for Bioethics (ICB)¹⁵¹ is of the opinion that competent adults should have the right to prepare an advance directive, stemming from their right to self-determination and their related rights to bodily integrity, privacy and dignity. The ICB takes the view that the instrument of the advance directive allows individuals to govern their future medical treatment and care, should they become incapacitated, in a way that reflects their personal values and beliefs. Equally, the ICB recognises and supports the right of those who do not wish to make an advance directive and there should be no obligation on an individual to do so.

The ICB believes there is both a need and an opportunity to develop a legal framework for advance directives to facilitate their use and implementation.

Does Personal Autonomy Have Limitations?

Few decisions are as consequential as those related to an individual's health, therefore it is understandable that individuals wish to make their own healthcare choices. While an individual might want to express the right to self-determination, any decisions regarding medical treatment will, in all likelihood, be influenced by the views of third parties (namely, the individual's doctor, family or friends). This emphasises the interdependence of all individuals within society, irrespective of an individual's wish to be wholly autonomous.^{152,153,154} Moral values are often culturally relative, and it has been suggested that the Western concept of autonomy, which emphasises self-determination, should consider lending more weight to family and community decision-making. Notably, autonomy must be balanced with other morally important concepts in the healthcare provider-patient relationship, including loyalty, integrity, solidarity and compassion.¹⁵⁵ In traditional Chinese society, largely based on Confucianism, individuals are viewed primarily in terms of their relationships to others.¹⁵⁶

In a discussion document produced by the Medical Council (of Ireland) in September 2006, the Medical Council stated, "where a competent adult patient makes a specific and informed decision to refuse future medical treatment in the event of his/her incapacity, this decision should be respected".¹⁵⁷ Competent individuals can reasonably expect a doctor to respect whatever decision they make regarding their treatment, even if the doctor believes that it is an incorrect or irrational

¹⁵⁰ Kutner, *op. cit.*

¹⁵¹ Hereafter the Irish Council for Bioethics will be referred to as the ICB.

¹⁵² German National Ethics Council, *op. cit.*, p.43.

¹⁵³ The President's Council on Bioethics *op. cit.*, p.88.

¹⁵⁴ *J.M. v The Board of Management of St. Vincent's Hospital*, *op. cit.*, p.325. Mr. Justice Finnegan suggests that the ward's decision regarding her treatment was influenced by her desire to please her husband.

¹⁵⁵ Gostin, LO 1995. Informed consent, cultural sensitivity, and respect for persons. *Journal of the American Medical Association*, 274 (10): 844-845.

¹⁵⁶ Leininger, M 1991. The theory of culture care diversity and universality, in M Leininger (ed.) *Culture care diversity and universality: A theory of nursing*. National League for Nursing Press, New York, p.5-68.

¹⁵⁷ Medical Council of Ireland, 2006, *op. cit.*, p.4.

decision in light of the potential benefit of the proposed treatment.¹⁵⁸ However, an individual's right to self-determination is not absolute, and as such one individual cannot compel another individual to act against his or her conscience.^{159,160,161,162}

All patients have a duty to respect any doctor or healthcare professional who treats them, and they have a responsibility not to put undue pressure on these healthcare professionals with unrealistic or illegal treatment demands, e.g. with requests for euthanasia or assisted suicide. As autonomous individuals themselves, any doctor or other healthcare professional is entitled to object to undertaking treatment decisions outlined by a patient, in an advance directive or otherwise.¹⁶³ Nonetheless, just as there are constraints on the exercise of patient autonomy, so there are constraints on the impact of professionals' conscientious objections. Healthcare professionals still have a duty of care towards any patient even in the event of disagreeing with the terms of the patient's advance directive. This implies that they should continue to care for the patient until another healthcare professional can be located who is willing to uphold the patient's treatment decisions.^{164,165,166}

The rights of another group, namely the family, also need to be considered in relation to prospective medical decision-making. In practice, families often play a significant role in end-of-life decisions, regardless of whether or not there is an advance directive in existence. In all probability, the decisions taken by an individual in relation to his or her future healthcare will have emotional and perhaps financial consequences for that individual's family. The views of the family may be particularly relevant in instances of disagreement surrounding proposed treatments, especially in cases where the patient involved has not prepared an advance directive.¹⁶⁷ In the *Ward of Court* case, Mr. Justice Lynch stated that the views of an individual's family, while not wholly determinative, should carry considerable weight in any decision regarding that individual's treatment and care.¹⁶⁸

The institution of the family is considered to be an integral part of society and the rights of the family are clearly outlined under Article 41 of the Constitution of Ireland, which states that: "1. The State recognises the Family as the natural primary and fundamental unit group of Society, and as a moral institution possessing inalienable and imprescriptible rights, antecedent and superior to all positive law. 2. The State, therefore, guarantees to protect the Family in its Constitution and authority, as the necessary basis of social order and as indispensable to the welfare of the Nation and the State." In terms of medical decision-making, these rights entitle an incompetent individual's

158 German National Ethics Council, *op. cit.*, p.43.

159 British Medical Association, 2000, *op. cit.*, p.11.

160 Italian National Bioethics Committee, *op. cit.*, p.11.

161 National Ethics Council, *op. cit.*, p.44.

162 Palazzani, L 2004. Advance Directives and Living Wills. *Neurorehabilitation*, 19 (4): 305-313.

163 *Airedale N.H.S. Trust v Bland*, *op. cit.*, Lord Goff p.377.

164 Medical Council of Ireland, 2004, *op. cit.*, p.12.

165 General Medical Council, *op. cit.*, p.16.

166 British Medical Association, 2000, *op. cit.*, p.11.

167 *Airedale N.H.S. Trust v Bland*, *op. cit.*, Sir Stephen Brown p.332.

168 *In the matter of a Ward of Court*, *op. cit.*, Mr. Justice Lynch p.99.

family to have the family's views regarding that patient's treatment taken into account in discussions with the medical profession. However, in the case of an individual who has been made a ward of court, the views of the family cannot override the ruling of the courts regarding that individual's treatment.¹⁶⁹

Interestingly, in a public survey of 500 adults conducted by Taylor Nelson Sofres Market Research Board of Ireland (TNS MRBI) for the ICB in 2005, 72% of respondents stated that they would prefer their next of kin to make healthcare decisions on their behalf if they were incapable of doing so, with only 21% preferring to leave such decisions to their doctor.¹⁷⁰ However, the results of the public consultation for this opinion document suggest that, in addition to wanting to make their own decisions regarding their future treatment, the wish to avoid burdening their family with end-of-life decisions is also an important factor for many individuals when choosing to draw up an advance directive.¹⁷¹

The responsible exercise of individual autonomy could arguably be said to include full and frank discussions with family members in relation to decisions taken by individuals about their future healthcare. Nonetheless, any preferences contained in an advance directive should take precedence over the views of the family. In order to facilitate the co-operation of family and friends in ensuring that an advance directive is followed, it is considered prudent for individuals to make those close to them aware that they are preparing an advance directive and to discuss their treatment preferences with these people beforehand. It is envisaged that such prior discussion would reduce the incidences of conflict and disagreement regarding treatment in the future.

The interdependency and the interconnection of individuals within society can also be manifest in the right of the State to intervene in certain instances and override the rights of an individual to protect society at large, e.g. if the individual is suffering from a contagious disease, he or she can be treated in quarantine.^{172,173} John Stuart Mill made reference to such interventions in his "liberty principle", where he stated that, "the only purpose for which power can be rightfully exercised over any member of a civilised community, against his/her will, is to prevent harm to others".¹⁷⁴ The intervention of the State in such circumstances stems from its duty to uphold the common good and to protect the rights and best interests of its citizens, based on the ethical principles of beneficence, nonmaleficence and justice. The question arises, however, how far can the rights of the State legitimately impinge on the rights of an autonomous individual?

169 *ibid.* Mr. Justice Lynch p.90 and p.99.

170 The remaining breakdown of the answers were as follows: 2% preferred the courts to decide and 5% did not know. See Irish Council for Bioethics and TNS MRBI, *op. cit.*

171 See Appendix 1, The Public Consultation; Just over 69% of respondents stated they would consider drafting an advance directive to avoid burdening their family with end-of-life decisions.

172 Ryan, *op. cit.*, p. 106.

173 Donnelly, *op. cit.*, p.19.

174 Mill, *op. cit.*

It has been argued that if an individual is informed of and has contemplated the potential consequences of a given treatment decision and is still willing to outline this decision in an advance directive, then the individual's preference should be respected.^{175,176} Understandably, certain preferences, such as the refusal of life-sustaining treatment, may conflict with a State's considerations of care towards an individual, because such a treatment refusal could be considered to be against the best interests of the individual concerned. Nevertheless, while the principles of beneficence and nonmaleficence need to be taken into account in these situations, they need to be balanced against the individual's right of self-determination regarding his/her body.

Others maintain that an individual's preferences in an advance directive should not be the only factor taken into account when deciding treatment options¹⁷⁷ and that the principle of the protection of life and the medical duty of care should have some relevance.^{178,179,180} The conflict between the State's right to preserve life and an individual's right to self-determination can be difficult to resolve,¹⁸¹ even through the avenue of the courts. Notwithstanding these difficulties, similarly to an individual's right to self-determination, the State's right to preserve life is not absolute in all cases.^{182,183} One could argue that by overruling an advance directive, the State would, in the vast majority of cases, be misusing its protective obligations to preserve life, when in fact it should use these obligations to support and safeguard individual freedoms, not to limit them.¹⁸⁴

Conflicts between an individual and the State may also arise due to the fact that some State healthcare institutions may espouse a particular religious ethos. Should the content of an individual's advance directive conflict with the ethos of the institution in which they are being treated, implementation of the directive could be problematic. In the majority of such cases, it should be possible to transfer the patient to another institution willing to accede to the wishes expressed in the advance directive. However, in the small minority of cases where it is not feasible to transfer the patient either because no alternative institution is available, or the transfer would place an undue burden on the patient involved, such conflicts may be more difficult to resolve.¹⁸⁵ In such instances, the onus should be on the healthcare institution to justify why it is unable to accede to the wishes outlined in the advance directive. Ultimately, the resolution of these more intractable cases, involving conflicting rights will almost certainly require adjudication by the courts.

175 Michalowski, S 2005. Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right. *The Modern Law Review* 68 (6): 958-982.

176 Italian National Bioethics Committee, *op. cit.*, p.15.

177 The President's Council on Bioethics, *op. cit.*, p.82.

178 Michalowski, *op. cit.*

179 Tonelli, MR 1996. Pulling the Plug on Living Wills. A Critical Analysis of Advance Directives. *Chest* 110: 816-820.

180 Irish Bishops' Committee for Bioethics, 2002. *End of Life Care: Ethical and Pastoral Issues*, p.4. Accessed on 2, March 2006 at: <http://www.healthcare-ethics.ie/endoflifecare.html>

181 *Airedale N.H.S. Trust v Bland*, *op. cit.*, Mr. Justice Hoffman p.352: "There is no morally correct solution, which can be deduced from a single ethical principle like the sanctity of life or the right of self-determination. There must be accommodation between principles, both of which seem rational and good, but which have come into conflict with each other.

182 *In the matter of a Ward of Court*, *op. cit.*, Mr. Justice Lynch p.94 and Mrs. Justice Denham p.160.

183 *Airedale N.H.S. Trust v Bland*, *op. cit.*, Lord Keith p.362, Lord Goff, p.367 and Lord Mustill, p.395.

184 German National Ethics Council, *op. cit.*, p.51 and 52.

185 For example, despite the Supreme Court ruling in the *Ward of Court* case, no hospital was willing to accede to the removal of treatment from the ward and she died at home in the care of her family. See Hanafin *op. cit.*, p.132.

However, since the Constitution, under Article 40.1, recognises all individuals as being equal, it could be argued that individuals' advance directives should be followed irrespective of the fact that they may or may not subscribe to the same religious ethos as the hospital where they are being treated. Such a situation could arise particularly where the hospital with a religious ethos is State funded. The corollary of this situation is also true, in that an individual's advance directive reflecting personal or religious beliefs should also be upheld.

The principle of respect for autonomy restricts healthcare interventions to those that respect the decision-making capacity of a competent adult. However, the principle of respect for autonomy is, itself, limited. The principle is not absolute and must be balanced against other ethical principles and values, such as beneficence, nonmaleficence, justice, integrity and solidarity, thereby recognising the interdependency and the interconnection of individuals within society.

A healthcare professional is not at liberty to judge that a patient's decisions are either incorrect or irrational simply because they are at variance with the professional's opinion or values. Nonetheless, the ICB recognises that a competent individual's rights in healthcare decision-making are not absolute and that individuals cannot compel healthcare professionals or other parties to act against their conscience (or the law) to accede to their wishes regarding treatment. Nevertheless, healthcare professionals still have a duty of care to an individual; therefore, they should continue to care for the patient until another healthcare professional can be located who is willing to uphold that patient's treatment decisions.

Prospective healthcare decisions taken by an individual will almost invariably have consequences, both emotional and perhaps financial, for that individual's family. In recognition of this fact, the ICB recommends that individuals discuss the decisions outlined in their advance directives with their family. However, a competent individual's advance directive should not be overridden by the wishes of the family, unless the individual has specifically given his or her family the power to do so in an advance directive or healthcare proxy.

While acknowledging the State's duty to protect the rights and best interests of its citizens, including preserving their lives, the ICB believes that this duty encompasses supporting individual freedoms such as respecting an individual's advance directive, once the provisions within such a directive are themselves legal.

Determining Preferences for the “Future Self”

It is well recognised that an individual's views and values towards his or her treatment could change with age, the onset or progression of an illness or indeed in the face of future medical advances; therefore, should such decisions regarding treatment be binding on a future self? It has been argued that an individual's previous treatment preferences are important and should be taken into consideration, as they can offer an insight into that individual's personal beliefs and how they would wish to be treated, but that such preferences should not be binding in relation to the current treatment situation.^{186,187,188} However, honouring individuals' advance directives respects their “right and earned prerogative” to control and shape their life as a whole.¹⁸⁹

Acknowledging that an individual's views regarding medical treatment are liable to change with time, the question arises whether these changes reflect a change in that individual's identity; in other words, can he or she still be considered as the same person? Specifically when discussing advance directives, if an individual has become incompetent since drafting an advance directive can he or she still be considered identical to the author of the advance directive? In some situations, e.g. in cases of people with dementia, it is difficult to determine if the now incompetent individual still has the same views and values regarding treatment. Therefore, should the “previous self” be able to dictate the treatment of the “future self”?¹⁹⁰

Profound personality changes, which can occur during the course of disease, call into question whether there is psychological continuity and connectedness between the person who expressed precise opinions when s/he was in good health or only slightly affected and the same person in an advanced phase of the disease.¹⁹¹ It has been argued by supporters of the discontinuity thesis that an individual with dementia is a new person and their previous self who authored the advance directive, while competent, no longer exists; therefore, that previous self's advance directive would no longer be morally or legally binding.¹⁹² This rationale has given rise to the suggestion that a permanently unconscious patient could be considered to be “a nonperson ward of the state with no history, no family, and no interests in what happens to him or her”; and as such these individuals could be used in medical research or have their organs harvested for donation before terminating their life.¹⁹³

However, psychological continuity is not the only determinant of identity. In Judeo-Christian tradition, the individual and the body are integrally connected, when the body is dead, we consider the person to be dead. Defining those who no longer possess psychological continuity and connectedness as dead distinguishes the death of the person from the death of the body.

186 The President's Council on Bioethics, *ibid.* p.84.

187 Italian National Bioethics Committee, *op. cit.*, p.23.

188 Scottish Council on Human Bioethics, 2006a, *op. cit.*

189 Olick, RS 2001. *Taking Advance Directives Seriously. Prospective Autonomy and Decisions near the End of Life*. Georgetown University Press, Washington D.C., USA, p.138.

190 Tonelli, *op. cit.*

191 Parfit, D 1984. *Reasons and persons*. Oxford: Clarendon Press. 545p.

192 Olick, *op. cit.*, p.138.

193 *ibid.* p.150.

This is clearly at odds with social and cultural norms, where many families continue to care for their loved ones who may suffer dementia or brain injuries despite them not being the person they once were. Opponents of the discontinuity thesis also point out that illness, incapacity and death are all stages in a unitary life. Rather than seeing ourselves solely as the sum of our experiences, we can view ourselves as persons who have a history, a past, present and future, in which choices, experiences and relationships all play a part.¹⁹⁴ It is this narrative that binds all the stages of our life together and makes life comprehensible. The past, present and future are all connected, and choosing one course of action over another at any given moment will have consequences for the self, both immediately and in the future. Part of being a competent autonomous person is the ability to project into the future. Therefore, it can be argued that the time when the advance directive was drafted should be considered as the period in an individual's life when that individual was most decisive and, thus, the advance directive should govern all future medical decisions.¹⁹⁵

Nonetheless, it must be recognised that healthcare decisions made in advance are subject to a greater risk of miscalculation than those decisions made contemporaneously. In order to address this difficulty, an analogy has been drawn between the parent-child relationship and that of the former/present self.¹⁹⁶ Parents are given authority to make decisions on behalf of their children who lack capacity, as long as the decision is deemed to be in the best interest of the child. The parent's decision is open to scrutiny by the courts and can be challenged by other third parties who have an interest in the child. While a direct parallel cannot be drawn, it is useful to view the former self as the parent of the present self, with the moral authority to make decisions on behalf of the present self who now lacks capacity to do so. This decisional authority exercised by the former competent self is subject to the caveat that the healthcare decisions made by the former self are open to scrutiny by third parties who believe that the best interests of the present self are not being served.¹⁹⁷ Allowing the present self's family and carers a limited opportunity to perform this scrutiny recognises the interests of those parties as well as the interests of the present self.

While the ICB accepts that illness affects the personality of an individual it does not fundamentally alter that individual's identity, rather illness represents another stage in that individual's life. The ICB takes the view that an advance directive should be regarded as a more authoritative expression of an individual's wishes, than any presumed alteration of the directive as a result of illness-induced personality change. Therefore, an advance directive should be respected unless it is demonstrably contrary to the wishes of the now incapacitated individual, with the onus falling on the party wishing to challenge the advance directive.

194 MacIntyre, A 1984. *After Virtue. A Study in Moral Theory*. University of Notre Dame Press, USA, p.218.

195 The President's Council on Bioethics, *op. cit.* p.85.

196 Maclean, A 2006. Advance Directives, future selves and decision-making. *Medical Law Review*, 14: 291-320.

197 For an example of a case in which the advance directive of an individual was challenged by a third party see *HE v A Hospital N.H.S. Trust* [2003] 2 FLR.

Content and Format of an Advance Directive

Informed Consent and the Provision of Information

An individual is, generally, presumed to be competent to make decisions regarding his or her future medical treatment unless proven otherwise.¹⁹⁸ One of the central tenets of self-determination is that in order for individuals to make a decision to consent to or refuse a specific treatment, they should ideally be fully informed about their treatment options. This principle of informed consent is underpinned by the duty of the doctor to provide information and advice in a format that prospective patients will understand and to discuss the relevant issues with the individual patients to aid their decisions.¹⁹⁹ The advice provided could include relevant information on the existing treatment options available for different illnesses and conditions, including the potential risks and benefits associated with each, and could also involve identifying the possible consequences of choosing or not choosing a particular treatment.^{200,201,202} While the principle of informed consent is there to assist an individual in making autonomous choices regarding medical treatment, it has also been cited as one of the main reasons for arguing against the validity of advance directives.²⁰³ Given the difficulties and complexity of an individual being fully informed in a contemporary medical situation, how can an individual be fully informed to consent to or refuse treatment for a future situation that has not yet arisen?²⁰⁴

Admittedly, with certain medical conditions, such as Motor Neurone Disease,²⁰⁵ spino-cerebellar ataxia²⁰⁶ or PVS, there is a well-established prognosis, which the patient can be briefed on in advance. In these circumstances individuals could realistically outline their treatment decisions in an advance directive. However, it has been argued that patients could not be truly informed about all future medical eventualities that could occur, nor could they be fully aware of the potential developments in medical science that could be made during the period between when the advance directive is drafted and its implementation.²⁰⁷ Using that rationale, any decisions about treatment

198 Mental Capacity Act, *op. cit.*, section 1 (2).

199 Medical Council of Ireland, 2004, *op. cit.*, p.13.

200 Mental Capacity Act, *op. cit.*, section 3 (4).

201 German National Ethics Council, *op. cit.*, p.47.

202 Bachinger, *op. cit.*, p.4.

203 Campbell *op. cit.*

204 Fagerlin and Schneider, *op. cit.*

205 Motor Neuron Disease is an incurable, progressively degenerative neurological illness, which results in the loss of the voluntary muscle activity of motor neurones, which control voluntary muscle activity such as speaking, walking, swallowing, and breathing. MND does not affect touch, taste, sight, smell or hearing and does not directly affect bladder, bowel or sexual function. Also, in the majority of cases of MND, the patient's intellect remains unaffected.

206 Spino-cerebellar Ataxia is an incurable, congenital, progressively degenerative brain condition. The gradual deterioration of the spinal cord, the cerebellum, results in the loss of muscle coordination and movement and eventually the ability to speak. Despite this, the individual is likely to remain mentally competent until death is imminent.

207 Campbell *op. cit.*

outlined in an advance directive can rarely be fully informed and the validity of such decisions would be questionable, or, as has been suggested, “a living will made by a patient who was not fully informed lacks the moral weight of an autonomous and contemporaneous choice”.²⁰⁸

However, given that a competent individual can forgo receiving any information yet still consent to or refuse medical treatment in contemporary situations,²⁰⁹ the perceived lack of information about future medical eventualities when drafting an advance directive may not be a sufficient reason to doubt the validity of a directive. Furthermore, the problem of the lack of information to make a treatment decision can be overcome if individuals update their advance directives to take account of any progress in medical science, thus ensuring that their decisions are based on the most relevant information available.

Obtaining professional advice and counselling before drafting an advance directive can assist in the clear, understandable and accurate recording of an individual's treatment wishes in the directive.^{210,211,212,213} In addition to an individual's GP, such advice and counselling can be obtained from a number of sources, for example nurses and other healthcare professionals, or it could be obtained in the form of legal and practical advice from a solicitor or legal adviser, or in the form of religious and spiritual advice.²¹⁴ It has been noted that individuals may have unrealistic expectations with regard to what certain treatments can or cannot do for them,^{215,216} e.g. Cardiopulmonary Resuscitation (CPR),²¹⁷ which could influence the wording of their advance directives. In relation to requests for treatment, any unrealistic, unfeasible or unreasonable demands given in an advance directive could be problematic and are less likely to be adhered to, thus at least partially negating the function of the directive. In addition, from a legal perspective it is usually necessary to be specific in outlining preferences for particular treatment scenarios, and this level of expected specificity could be difficult to achieve without adequate counselling.

However, while recommending that an individual avail of advice and counselling before drafting an advance directive, this advice should not be a prerequisite for a directive to be followed. Certain individuals may not wish to take counsel on the matter and they might not be able to avail of such advice for personal, financial or other reasons.²¹⁸

208 The President's Council for Bioethics, *op. cit.*, p.84.

209 German National Ethics Council, *op. cit.*, p.47.

210 Alzheimer Europe, 2005b. *Advance Directives: A position paper*. p.5 and 9. Accessed on 13, February at: <http://www.alzheimer-europe.org/upload/SPTUNFUYGGOM/downloads/7939D9FD4CEE.pdf>

211 German National Ethics Council, *op. cit.*, p.64-65.

212 Bachinger, *op. cit.*, p.10.

213 British Medical Association, 2000, *op. cit.*, p.6.

214 Teno, JM, Stevens, M, Spornak, S and Lynn, J 1998. Role of Written Advance Directives in Decision Making. Insights from Qualitative and Quantitative Data. *Journal of General Internal Medicine* 13: 439-446.

215 British Medical Association, 2000, *op. cit.*, p.6.

216 British Medical Association, 2001. *Decisions Relating to Cardiopulmonary Resuscitation. A Joint Statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing*. British Medical Association, London, p.9.

217 Cardiopulmonary Resuscitation (CPR): Restoration of cardiac output and pulmonary ventilation by artificial respiration and closed-chest massage after cardiac arrest and apnoea.

218 Scottish Executive, 2005. *The New Mental Health Act: A Guide To Advance Statements*. Edinburgh, p.11.

Nonetheless, availing of advice on the content, structure and wording of the directive can reduce the chances of it not being followed. Moreover, every time advice is provided it should be based on the most up-to-date medical and scientific information available to ensure that individuals are sufficiently briefed before outlining their decision in their advance directive.²¹⁹ This counselling process should result in the drafting of more concise, focused and pertinent advance directives that are more likely to be read and adhered to.²²⁰

The recommendation of obtaining professional advice before drafting an advance directive highlights the importance of communication between the authors of directives and their advisers. Notwithstanding the importance of professional advice, communication is not unidirectional, in that the individual drafting the directive also imparts views, beliefs and preferences on treatment; the adviser, e.g. the GP, takes this information into consideration and counsels the individual accordingly. In addition, these discussions enable individuals to clarify their wishes regarding each treatment option, in light of the information provided to them, thus, helping them to come to terms with the consequences of the decisions in their advance directive.

The process of communication regarding the treatment decisions in an individual's advance directive should also be ongoing and progressive. This would enable an individual to reassess certain treatment preferences in the light of new information regarding recent medical developments. In addition, individuals' preferences regarding treatment may have altered over time, following changes in their personality or their perspective on life in general as a result of ageing, illness, bereavement of loved ones or other life experiences.^{221,222,223,224}

Given the importance of the concept of informed consent to the right of self-determination, the ICB recommends that an individual should obtain up-to-date information and advice before preparing an advance directive. This information can be provided by a number of sources in the form of medical, legal, religious or spiritual advice. While acknowledging that availing of such professional advice should not be obligatory for the implementation of an advance directive, the ICB takes the view that this advice can assist in the structure, wording and applicability of an advance directive.

219 Fagerlin and Schneider, *op. cit.*

220 Teno *et al. op. cit.*

221 Seymour, J, Gott, M, Bellamy, G, Ahmedzai, SH and Clark, D 2004. Planning for the end of life: the views of older people about advance care statements. *Social Science & Medicine* 59: 57-68.

222 Michalowski, *op. cit.*

223 Teno *et al. op. cit.*

224 Fagerlin and Schneider, *op. cit.*

Scope of an Advance Directive

When advance directives were first proposed in the form of a living will, it was envisaged that they would outline an individual's refusal of further treatment if that individual entered an irrecoverable vegetative state. It was also considered that such treatment refusals could be based on an individual's specific religious beliefs.²²⁵ In addition, the advance directive offered the possibility of identifying a third party to be involved in discussions with the healthcare team regarding the future treatment of the author of the directive.

Since this original proposal, the potential scope and coverage of advance directives has expanded and can now cover a multitude of issues surrounding treatment and care in general, but particularly at the end of life, including both requests for and refusals of treatment.²²⁶ As noted previously, the treatment preferences in an advance directive must be legal within the jurisdiction where the directive is drawn up. Therefore, in the vast majority of countries a directive could not contain requests for assisted suicide or euthanasia.

Furthermore, the results of the public consultation conducted for this opinion indicated that individuals would like their advance directives to cover, among other things, life-prolonging treatment, pain medication and end-of-life care, but also their preferences regarding organ donation and the donation of their body for educational purposes.²²⁷ This suggests that the advance decisions individuals make, especially relating to their end of life, go beyond just medical treatment considerations. For instance, it has been intimated that a request not to be placed in a nursing home is one of the most common preferences outlined in an advance directive.²²⁸ In fact, the British Medical Association (BMA) guidelines on advance statements note that advance directives are not restricted to cover hospital care but can also include decisions on care at home, in a hospice or a nursing home.²²⁹ Furthermore, the General Medical Council (GMC) in the UK, advocates that decisions on the care of dying patients should consider individuals' wishes on all aspects of their medical care, including their place of care, as well as their need for religious and spiritual support.²³⁰

A study carried out by the Irish Hospice Foundation (IHF) in 2004 indicated that a majority of people questioned (67%) wished to be cared for at home if they were dying, whereas a minority of respondents wished to be cared for in a hospital (10%), hospice (10%) or nursing home (5%).^{231,232} Moreover, in that 2004 survey, respondents also expressed clear views about other issues that were important to them at their end of life, namely, to be surrounded by people they love (68%),

225 Kutner *op. cit.*

226 Alzheimer Europe, 2005b, *op. cit.*, p.6, 7.

227 See Appendix 1, The Public Consultation, for the full breakdown of the preferences people would want in their advance directives.

228 O'Neill, D 2001. Present, rather than advance directives. *The Lancet* 358: 1921-1922.

229 British Medical Association, 2000, *op. cit.*, p.4.

230 General Medical Council, *op. cit.*, p.15.

231 Irish Hospice Foundation, *op. cit.*, p.10.

232 It should be noted that despite such wishes regarding the preferred place of death, the majority of people in the Republic of Ireland do not die at home. For example, in 2003 only approximately 25% of all deaths were recorded as home deaths (domiciliary). See Central Statistics Office, 2005. *Report on Vital Statistics 2003*. The Stationery Office, Dublin, p.73. Accessed on 10, August 2006 at: <http://www.cso.ie/releasespublications/documents/population/current/poppro.pdf>

to be free from pain (55%), to be conscious and able to communicate (35%).²³³ Individuals often make reference to such wishes in their advance directives in the form of personalised value statements.^{234,235,236,237}

Treatment Refusals

Given the right to self-determination, treatment decisions, particularly refusals of treatment, outlined in an individual's advance directive should be followed, provided they are legal. This situation can be complicated by the definition of what constitutes medical treatment. There is still some disagreement in some quarters over whether or not ANH should be classified as a treatment.^{238,239} For example, the Medical Council (of Ireland) guidelines highlight the basic need for everyone to have access to nutrition and hydration, and that this access should be maintained wherever reasonable and practical.²⁴⁰ In addition, a guidance statement to the nursing profession, An Bord Altranais (the Irish Nursing Board), advises nurses not to participate in the withdrawal or termination of ANH from an individual but to continue to provide nursing care to that person.²⁴¹

In an address on life-sustaining treatments and the vegetative state in 2004, Pope John Paul II identified the provision of ANH not as a medical treatment but as a natural means of preserving life, and as such it was, in principle, morally obligatory to provide ANH.²⁴² The Pope's statement has been interpreted as saying that ANH should be provided in all cases unless it is considered inappropriate or burdensome on the individual involved.²⁴³ Interestingly, the Italian National Bioethics Committee, while recognising ANH as a medical procedure, also regards ANH as morally mandatory unless it is overly burdensome for the patient.²⁴⁴ From a legal perspective in Ireland, however, ANH is currently considered a medical treatment.²⁴⁵ As a result, individuals should be able to refuse ANH, in the same way that they might choose to forego any other medical treatment, either contemporaneously or in an advance directive if they so wish. It should be noted, however, that due to the emotive symbolism associated with the provision of food and water, whether artificially or not,

233 The remaining breakdown of the answers were as follows: 34% to be at home; 32% to have medical and nursing support readily available; 19% to have spiritual support available; and 11% to be in a private space. See Irish Hospice Foundation, *op. cit.*, p. 23

234 British Medical Association, 2000, *op. cit.*, p.3.

235 Irish Bishops' Committee for Bioethics, *op. cit.*, p.7.

236 The President's Council on Bioethics, *op. cit.*, p.57.

237 Alzheimer Europe, 2005b, *op. cit.*, p.10.

238 Casarett, D, Kapo, MD and Caplan, A 2005. Appropriate Use of Artificial Nutrition and Hydration – Fundamental Principles and Recommendations. *New England Journal of Medicine* 353 (24): 2607-2612.

239 Cranston, RE 2001. *Withholding or Withdrawing of Artificial Nutrition and Hydration*. Accessed on 21, February 2006 at: http://www.cbhd.org/resources/endoflife/cranston_2001-11-19.htm

240 Medical Council of Ireland, 2004, *op. cit.*, p.34.

241 An Bord Altranais (Nursing Board) 1995. *Guidance issued by An Bord Altranais to the nursing profession following An Bord's consideration of the Supreme Court decision in the matter of "A Ward of Court" delivered on 27th July 1995*. Dublin, p.1.

242 Pope John Paul II 2004. *Address of John Paul II to the participants in the international congress on "Life Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas*. Accessed on 21, February 2006 at: http://www.vatican.va/holy_father/john_paul_ii/speeches/2004/march/documents/hf_jp-ii_spe_20040320_congress-fiamc_en.html

243 Catholic Health Australia, 2004. *Briefing Note on the Obligation to provide Nutrition and Hydration*. 6p.

244 Italian National Bioethics Committee, *op. cit.*, p.14

245 *In the matter of a Ward of Court*, *op. cit.*, Mr. Justice Lynch p.96, Mr. Justice Hamilton p.126, Mr. Justice O'Flaherty p.129, Mr. Justice Blayney p.143, 144, and Mrs. Justice Denham p.158.

there may still be some difficulties with doctors and healthcare professionals acceding to refusals of ANH outlined in advance directives.²⁴⁶ However, this is less likely to occur in situations where the administration of ANH has become overly burdensome for the patient concerned or is no longer medically appropriate.^{247,248,249}

As noted earlier, healthcare professionals with a conscientious objection to an individual patient's wishes regarding treatment, for example the refusal of ANH, can pass that individual on to another healthcare professional willing to comply with these wishes. Even in jurisdictions where refusals of treatment are legally binding, it may be necessary for additional criteria to be met before advance refusals of ANH will be followed.^{250,251} The *Mental Capacity Act* (2005) of England and Wales requires a specific written, signed and witnessed refusal of ANH (or other forms of life-sustaining treatment), regardless of any other treatment refusals contained elsewhere in an individual's directive.²⁵² These additional criteria should ensure that an individual has, at least, considered the consequences of a decision to refuse life-sustaining treatment, even if only while drafting that section of an advance directive.

The ICB acknowledges the right of individuals to refuse any form of medical treatment, including ANH or any other form of life-sustaining treatment, in an advance directive if they so wish.

Treatment Requests

There appears to be a general acceptance of treatment refusals in advance directives, provided the directive itself is considered valid. This may even be the case where the decisions may seem irrational to the healthcare professionals tasked with abiding by them.^{253,254} The same acceptance is certainly not shown with regards to *treatment requests* outlined in advance directives, though this can vary between different countries and jurisdictions. In the Netherlands, for example, requests for euthanasia can be made in advance directives, under the *Termination of Life on Request and Assistance with Suicide Act* (2002) but the acceptance of such requests is highly dependent on the fulfilment of stringent criteria related to due care.^{255, 256} It has also been argued that the very nature

246 Casarett *et al. op. cit.*

247 Scottish Council on Human Bioethics, 2006b. *Position Statement: Withdrawing or withholding of nutrition and/or hydration*. Accessed at www.schb.org.uk

248 Cranston, *op. cit.*

249 General Medical Council, *op. cit.*, p.37.

250 The President's Council on Bioethics, *op. cit.*, p.60.

251 Casarett *et al. op. cit.*

252 *Mental Capacity Act*, *op. cit.*, section 25 (5) and 25 (6).

253 British Medical Association, 2000, *op. cit.*, p.5.

254 *Airedale N.H.S. Trust v Bland*, *op. cit.*, Sir Thomas Bingham, p.334, 335 and Mrs. Justice Butler-Sloss p.342.

255 Health Council of the Netherlands, 2002, *Dementia*, The Hague, p.106.

256 van Delden JJM 2003. The unfeasibility of requests for euthanasia in advance directives. *Journal of Medical Ethics* 30: 447-451. Van Delden outlines the six rules of due care to be met in order for euthanasia to be legal in the Netherlands: "the physician must be convinced that the request of the patient was voluntary and well considered; the physician must be convinced that the suffering of the patient was unbearable and without prospect of relief; the patient must be informed about his/her situation and prospects; the physician together with the patient must be convinced that there was no reasonable alternative solution for the situation; at least one other physician must have seen the patient and must have given a written statement containing his evaluation of the four previous requirements; the ending of life must be performed in a professional and careful way."

of an advance directive precludes it from fulfilling these criteria and it is, thus, not feasible for advance directives to contain such requests.^{257, 258, 259}

However, it is worth noting that, outside the law regarding euthanasia and assisted suicide in the Netherlands, an advance directive cannot compel a doctor or other healthcare professional to provide a specific treatment. Despite this, the doctor or healthcare professional involved can provide the requested treatment if they deem it to be “within the scope of their professional responsibilities”.²⁶⁰ This attitude towards positive treatment requests in an advance directive is replicated in many areas.^{261, 262} For example, the BMA guidelines on advance statements provide that such a statement cannot insist on a specific procedure or treatment. The guidelines recommend that any requests should be respected and complied with if they are considered appropriate.²⁶³ As a case in point, it has been noted that patients may have an unrealistic opinion of the likelihood of survival following the administration of CPR, with many individuals envisaging a much higher success rate than actually occurs.^{264, 265, 266} Therefore, requests for CPR in advance directives may not always be followed, because the provision of this treatment may be considered as overly burdensome on a particular patient or even medically futile.

Decisions as to the appropriateness of a treatment request may look beyond what is medically indicated to include issues of resource and personnel availability. The point was made in *Airedale NHS Trust v Bland* [1993] that the duty of care of a medical institution should be limited to what it can reasonably provide for one individual, without neglecting another.²⁶⁷ Resources (e.g. finances, personnel, equipment and technology) in the healthcare system are finite but the demands placed on these resources are not; therefore, their allocation requires some degree of rationing.^{268, 269} In contemporary medical situations, this rationing of healthcare resources can result in certain treatment requests not being acceded to.²⁷⁰ Such limitations of resource allocation would also apply to prospective medical decision-making and the treatment requests outlined in an advance directive may not be acceded to. In terms of resource allocation, a patient does not have an autonomy-based right to demand particular treatments, which may be scarce or inappropriate.²⁷¹ Medical resources

257 van Delden, *op. cit.*

258 Health Council of the Netherlands, *op. cit.*, p.19-20 and 111.

259 Other than in the Netherlands, advance directives containing requests for euthanasia will not be followed under any circumstances.

260 Health Council of the Netherlands, *op. cit.*, p.100.

261 Italian National Ethics Committee, *op. cit.*, p.11.

262 General Medical Council, *op. cit.*, p.10.

263 British Medical Association, 2000, *op. cit.*, p.4.

264 O'Keeffe, ST 2001. Development and implementation of resuscitation guidelines: a personal experience. *Age and Ageing* 30: 19-25.

265 British Medical Association, 2001, *op. cit.*, p.9.

266 Fischer, GS, Tulskey, JA, Rose, MR, Siminoff, LA and Arnold, RM 1998. Patient Knowledge and Physician Predictions of Treatment Preferences After Discussion of Advance Directives. *Journal of General Internal Medicine* 13: 447-454.

267 *Airedale N.H.S. Trust v Bland*, *op. cit.*, Mr. Justice Hoffman p.357.

268 Larkin, GL, Weber, JE, and Moskop, JC 1998. Resource Utilization in the Emergency Department: The Duty of Stewardship. *The Journal of Emergency Medicine* 16 (3): 499-503.

269 National Health and Medical Research Council 1993. *Ethical considerations relating to health care resource allocation decisions*. Commonwealth of Australia, p.1.

270 Larkin *et al. op. cit.*

271 Dickenson, D and Hakim, NS 1999. Ethical Issues in Limb Transplants. *Postgraduate Medical Journal* 75: 513-515.

should be used in a way that is fair and just for all patients who may need them.^{272, 273} In addition, as previously noted, a common wish given in advance directives is a request not to be placed in a nursing home. However, this request may be dependent on the willingness of family members and/or friends to take on the responsibility of caring for the individual at home, as well as the availability of further home-help assistance from medical and care professionals in the locality.

From a legal perspective, a recent case in the Court of Appeal in England and Wales, *Burke v GMC* [2005], ruled that an individual was not entitled to insist on receiving a particular medical treatment that the doctor considered to be “adverse to the patient’s clinical needs”.²⁷⁴ This case involved a man, Mr. Oliver Leslie Burke, who suffered from spino-cerebellar ataxia and wished to ensure that he would receive ANH in the future when he was no longer able to communicate with the healthcare professionals treating him. The court ruled that under their duty of care, doctors would ordinarily provide ANH to all patients, unless they did not want to receive it or unless it was not clinically indicated. In such circumstances the patient’s request to have his or her life sustained by ANH would only underscore the doctor’s duty to treat the patient, as opposed to it being the sole reason for providing the treatment.²⁷⁵

The ICB supports the view that, wherever feasible, treatment requests made in an advance directive should be respected. Positive requests for medical treatment should be taken into account and the provision of treatment should be based on the relevance of the proposed treatment to the current situation and the feasibility of providing it given the personnel, technical and financial resources available. However, the endorsement of such requests does not include demands of individuals for treatment that the doctor deems futile. The reason for refusing to endorse such requests is that the use of futile treatments has consequences for the equitable and just allocation of healthcare resources to society as a whole.

Specificity of Advance Directives

By providing general preferences, based on their personal values and beliefs, in their advance directive, individuals are intending to guide their future medical treatment. However, unlike competent individuals from whom the relevance and meaning of their values and beliefs regarding their medical treatment and overall care can be ascertained directly through discussion with them, it can be difficult turning the value derived preferences listed in an advance directive into objective criteria for the treatment and care of a now incompetent individual.²⁷⁶ For example, an advance directive might state that an individual does not want to receive any heroic measures in the future, but it could be difficult for the healthcare team to determine what constitutes heroic treatment for

272 National Health and Medical Research Council 1993. *Ethical considerations relating to health care resource allocation decisions*. Commonwealth of Australia, p.2.

273 Larkin *et al.* *op. cit.*

274 *Burke, R (on the application of) v General Medical Council & Ors* [2005] EWCA Civ 1003, paragraph 31 and paragraph 54.

275 *ibid.* paragraph 32.

276 Emanuel, L 2000. How living wills can help doctors and patients talk about dying. *British Medical Journal* 320: 1618-1619.

that individual.²⁷⁷ Alternatively, individuals might state in their advance directives that they want their treatment to keep them comfortable, or to allow them to enjoy a decent quality of life, or even to enable them to experience a dignified death, but these wishes could mean different things to different people.^{278,279,280}

The difficulties in interpreting an individual's general preferences regarding treatment can mean that such wishes, while used in the overall assessment of potential treatment options, may not be afforded the same weight as more specific decisions regarding treatment.²⁸¹ Therefore, there may be some difficulty in giving such generalised advance directives the same standing in law as a more detailed directive containing specific treatment decisions.^{282, 283} However, some individuals perceive an advance directive as a tool to enable them to maintain involvement in their medical treatment by providing personalised guidance for future treatment decisions, without expecting such wishes to be legally binding^{284, 285} In addition, an advance directive containing general treatment preferences, which stem from an individual's values and beliefs, could potentially apply to a broader range of treatment scenarios and subsequently may not necessarily require review or updating in the face of future medical advances.

The degree of interpretation required for an individual's advance directive depends on the level of detail involved. For example, an advance directive that refused antibiotic treatment of infections if the individual was in PVS is quite clear-cut and could be followed directly. Refusals of treatment are, generally, more readily accepted and routinely included in advance directives, though they may still require some interpretation. As noted above, decisions about treatment in the case of PVS or other long-term coma conditions can be quite definitive, given the improbability of recovery. In such cases, advance directives refusing numerous forms of treatment, such as, antibiotic treatment, artificial ventilation, CPR and even ANH are regularly respected.

With other medical illnesses and conditions it could be difficult to determine when the wishes outlined in the advance directive should apply to the treatment to be provided. For example, individuals may wish to refuse life-sustaining treatment in the event that they develop some form of dementia and subsequent mental incompetence, but it could be difficult for doctors, healthcare professionals and even family members to agree to refusing treatment in the case of a patient with mild dementia who contracts another otherwise curable illness.^{286, 287} Therefore, to minimise the risk of misinterpretation or non-compliance with instructions contained in an advance directive it is

277 Alzheimer Europe, 2005b, *op. cit.*, p.9.

278 Michalowski, *op. cit.*

279 Irish Bishops' Committee for Bioethics, *op. cit.*, p.8.

280 Palazzani, *op. cit.*

281 British Medical Association, 2000, *op. cit.*, p.6.

282 *ibid.* p.3.

283 Michalowski, *op. cit.*

284 Italian National Bioethics Committee, *op. cit.*, p.17.

285 See Appendix 1, The Public Consultation: While 42% of the respondents to consultation stated they would want their advance directive to be strictly observed, 54.4% stated their directive should be followed as much as possible but not necessarily strictly observed, whereas the remaining 3.6% stated their advance directive should just be used as a reference.

286 Donnelly, *op. cit.*, p.65-66.

287 The President's Council on Bioethics, *op. cit.*, p.83.

often recommended that the directive should outline, in clear and unambiguous terms, not only the treatment the individual wishes to refuse/request but also the specific medical situations in which they intend that refusal/request to apply.^{288, 289, 290}

The need for clarity and specificity regarding treatment refusals is particularly important for advance directives that are intended to be legally binding. For instance, the *Mental Capacity Act* (2005) in England and Wales states that for a refusal of treatment to be considered valid, and therefore legally binding, it must be specifically outlined in the directive and it must apply to the current treatment situation.²⁹¹ Similar conditions are also applied to advance refusals of treatment under the *Living Will Act* (2006) of Austria.²⁹² Notwithstanding this requirement for specificity for an advance directive to be legally binding, there are still a number of reasons why an individual may not want to commit to making very specific decisions on a particular treatment. Individuals may not wish to limit themselves to very specific avenues of treatment that only apply to a narrow selection of treatment scenarios, thereby diminishing the applicability of their advance directive if these scenarios do not arise as described therein. Furthermore, individuals may not feel they are sufficiently informed regarding the effectiveness of a certain drug or therapy, particularly given the potential advances that could occur in the future, to make such definitive decisions on its use as a treatment. This highlights the importance of receiving sufficient relevant information from doctors and healthcare professionals before drafting an advance directive.

The content of an advance directive can encompass a number of different formats as outlined above, each of which has its own advantages and disadvantages, depending on the intended use of the directive. It is clear, therefore, that the implementation of an advance directive can be influenced not only by the decisions regarding treatment themselves, but also by the structure, format and presentation of the directive.

The ICB takes the view that for the decisions outlined in an advance directive to be considered legally binding, the directive should state, in clear and unambiguous terms, both the specific treatments to which the directive relates and the situations to which these decisions are intended to apply.

In other cases, individuals may wish to outline general preferences or a value statement regarding their future treatment and care in an advance directive that would be taken into account as opposed to being strictly legally binding. The ICB considers that such advance directives should also be accepted, but it recognises that such general statements may not be legally binding and may require more interpretation before they can be adhered to.

288 German National Ethics Council, *op. cit.*, p.49.

289 British Medical Association, 2000, *op. cit.*, p.3.

290 Biegler, P, Stewart, C, Savulescu, J and Skene L 2000. Determining the validity of advance directives. *The Medical Journal of Australia* 172: 545-548.

291 *Mental Capacity Act*, *op. cit.*, section 24-26.

292 Federal Act on Living Wills (Patientenverfügungs-Gesetz - PatVG), *op. cit.*, p.1.

Proxy Decision-Makers

The acceptability of an advance directive can be aided by the appointment of a proxy to make medical treatment decisions on behalf of the author of the directive and/or to interpret the treatment preferences or value statements outlined therein. One of the main benefits of nominating a proxy is that he or she can be involved in treatment discussions in the future when the author of the directive is incapacitated. This would enable the proxy to avail of the most up-to-date medical information and assess the wishes of the author of the directive in light of this new information. Given the problems of fully anticipating both the clinical and personal details of a particular case in advance, being able to adapt treatment decisions for the author of the directive according to the current treatment situation is extremely valuable.

Obviously, the degree of control the proxy can have in the decision-making process can, depending on the jurisdiction, be established by the author of the directive, *i.e.* the role of the proxy can range from just reiterating the treatment preferences as outlined in the directive to having full decision-making power. In some jurisdictions, legislation may also limit the decision-making power of the proxy, for example, in England and Wales someone nominated in a lasting power of attorney under the *Mental Capacity Act* (2005) can consent to or refuse treatment on behalf of the author of the directive, but can only make decisions on life-sustaining treatment if this is specifically stated in the advance directive.²⁹³ In Scotland under the *Adults with Incapacity (Scotland) Act* (2000), individuals can appoint a welfare attorney to make treatment decisions on their behalf in the event of their future incapacity, based on the individuals' best interests at the time but also incorporating their known wishes and the views of those close to the individual.^{294, 295} In Germany, it has been recommended that the powers of an appointed proxy should be curtailed to prevent the proxy from overriding a sufficiently clear and well-defined decision in an advance directive.²⁹⁶ As noted previously, the LRC has also recommended the introduction of limited medical decision-making authority to those named in enduring powers of attorney and also to personal guardians.²⁹⁷

It has been argued that the provision of such decision-making power to third parties, requires both regulation and guidance to help avoid possible abuses as well as misunderstandings and misinterpretation of an incapacitated individual's wishes.^{298, 299, 300} In addition, in situations where there is no advance directive, there may be little guidance for the appointed proxy on the patient's views toward particular medical interventions. Decisions may, therefore, be based on what the proxy might want and not what the incapacitated individual would want. To minimise such problems it is

293 *Mental Capacity Act*, *op. cit.*, section 11 (7 and 8).

294 *Adults with Incapacity (Scotland) Act* 2000. Section 1 and 16. Accessed on 16, February 2006 at: <http://www.opsi.gov.uk/legislation/scotland/acts2000/20000004.htm>

295 Campbell *op. cit.*

296 German National Ethics Council, *op. cit.*, p.63.

297 See the section entitled "Substituted and Assisted Decision-Making for Incapacitated Adults" for more details.

298 German National Ethics Council, *op. cit.*, p.63.

299 Alzheimer Europe, 2005b, *op. cit.*, p.8.

300 Brown, *op. cit.*

recommended that the proxy should be someone who is well known to and trusted by the person making the directive, though not necessarily a relative. This proxy would be someone with whom the individual can discuss his or her treatment wishes to ensure they will be upheld.

If an individual intends to nominate a proxy in an advance directive, and providing this person accepts the task, the author of the advance directive should discuss treatment preferences in detail with the proxy. This would help to clarify the views and wishes of the author of the directive for the proxy, who would be tasked with interpreting the directive should the author lose decisional capacity. In some cases, individuals may wish their proxy to be involved in the treatment discussions they have with their doctor and other healthcare professionals.

The ICB recommends the nomination of one or more proxies to facilitate the acceptability and implementation of the healthcare decisions outlined in an individual's advance directive. A proxy benefits from being involved in discussions regarding an incapacitated individual's treatment and care and can assess and interpret the wishes of the author of the directive in the light of the latest medical information available.

The ICB is of the opinion that a legislative framework for advance directives could also encompass the authority of nominated proxies to make healthcare decisions on behalf of another individual. One potential avenue for legislating the powers of proxies is through the expansion of the Powers of Attorney Act (1996) to enable both proxies and those nominated under powers of attorney to make decisions on an individual's medical treatment.

The Implementation of Advance Directives

Documenting an Advance Directive

While any advance treatment preferences or decisions given orally are very important there may be more risk of these oral wishes being misunderstood or misinterpreted.^{301, 302} Furthermore, it could prove difficult to verify an individual's previous wishes that were only given orally, which could lead to conflicts and disagreements over the proposed treatment options in the current situation. Therefore, considering the importance of the treatment preferences and decisions outlined in an advance directive, it is recommended that advance directives should be written, or otherwise reliably recorded (e.g. voice or video recorded).^{303, 304, 305, 306} Accurately recording an individual's preferences for treatment can reduce the likelihood of future conflicts, but what is more, can better ensure that the individual's treatment wishes will be implemented.

Once drafted, an advance directive should be attested by a witness, thus limiting the ability of others to question the validity of the advance directive in the future.^{307, 308, 309, 310} Moreover, if an individual nominates a proxy, this proxy can also verify that the advance directive was made as recorded by the author. The results of the public survey for this opinion document indicated that people wanted to ensure their advance directives were accurately recorded, with just over 46% of respondents stating they would prefer if their directive was documented in writing or recorded, while almost 48% of respondents stated they would prefer if their directives were both documented and outlined orally to their proxy.³¹¹

It should be noted, that both medicine and medical science are continually advancing, such that existing treatments and therapies may be improved and previously incurable illnesses may eventually be treatable. Such potential medical advances are often considered as reasons against preparing an advance directive based on the treatment options that exist when the directive is made.^{312, 313, 314, 315} It is, therefore, often recommended that individuals review and

301 German National Ethics Council *op. cit.*, p.53.

302 British Medical Council, 2000, *op. cit.*, p.6.

303 German National Ethics Council *op. cit.*, p.53.

304 Mental Capacity Act, *op. cit.*, section 25 (6).

305 Italian National Bioethics Committee, *op. cit.*, p.22.

306 Bachinger, *op. cit.*

307 Scottish Executive, *op. cit.*, p.8.

308 British Medical Association, 2000, *op. cit.*, p.9.

309 Alzheimer Europe, 2005b, *op. cit.*, p.11.

310 Bachinger, *op. cit.*

311 See Appendix 1, The Public Consultation: The remaining respondents (6%) stated they would prefer if their directives were outlined to a proxy.

312 Scottish Council on Human Bioethics, 2006a, *op. cit.*

313 Fagerlin and Schneider, *op. cit.*

314 Tonelli, *op. cit.*

315 Michalowski, *op. cit.*

update their advance directive on a relatively regular basis to take account of these medical improvements.^{316,317,318} The more recently an advance directive was reviewed, the more likely it is to be considered valid and, therefore, be implemented.

All forms of advance directives, but particularly those that are intended to be legally binding, should be accurately recorded, whether in writing or voice or video recorded, and attested by at least one witness. The ICB considers that such measures would help to ensure the authenticity and validity of an advance directive.

The ICB advises that individuals should review their advance directive regularly and should update it where necessary to reflect not only the relevant changes in medical science but also any changes in the individuals' values and beliefs, whether as a result of a change in their health status or otherwise, that might influence their decisions regarding treatment.

Revoking an Advance Directive

Following a review of an advance directive, an individual may wish to withdraw or revoke it, however, it is usually recommended that an individual can revoke an advance directive at any time, without the need to review it.^{319,320,321} Although, the level of competence required to revoke an advance directive varies between different jurisdictions, it is clear that an individual can revoke an advance directive when considered competent. However, if individuals are incompetent they may or may not be allowed to revoke their advance directive, for example, some states in the US allow incompetent individuals to revoke their directives, whereas others do not.³²²

It is often recommended that any withdrawal of an advance directive should be witnessed and made in writing,³²³ with some organisations even providing specific forms to be completed to revoke an advance directive.³²⁴ The condition of having to withdraw an advance directive in writing would thereby require some degree of competency on the part of the individual. Under the *Mental Capacity Act* (2005) of England and Wales, while the individual must be considered competent, the withdrawal of an advance directive need not be in writing, unless the directive refers to decisions on life-sustaining treatment.³²⁵ As already noted, if an advance directive is intended to be legally binding it needs to be accurately recorded, either in writing or otherwise, and witnessed. The preparation of a legally binding advance directive would, therefore, necessitate some level

316 Recommendations on the frequency of review of an advance directive vary from every 6 months, to every year, to every 3 years, or every 5 years.

317 British Medical Association, 2000, *op. cit.*, p.7.

318 Campbell, *op. cit.*

319 Bachinger, *op. cit.*

320 Scottish Council on Human Bioethics, 2006a, *op. cit.*

321 Georges, *op. cit.*, p.11.

322 Campbell, *op. cit.*

323 Alzheimer Europe, 2005a, *op. cit.*, p.7, 26 and 31.

324 Scottish Executive, *op. cit.*, p.15. (A copy of this form is shown as Sample 2 in Appendix 4).

325 *Mental Capacity Act*, *op. cit.*, section 24 (4 and 5).

of competence on the part of the author of the directive. It could be argued that given the legal ramifications of a binding directive, an individual would also require some level of competence to revoke such a directive.

While the oral withdrawal of an advance directive is often accepted in some jurisdictions, this withdrawal still needs to be accurately documented (e.g. in the individual's medical record) to ensure that there is no confusion in the future and the individual is not treated according to wishes they expressed in an old advance directive that they have subsequently revoked. A written and witnessed withdrawal is, thus, more likely to be accurately recorded and can be verified in the future if necessary.

Questions have been raised about allowing incompetent individuals to revoke their own advance directive. It has been argued that permitting incompetent individuals to revoke their advance directives defeats the purpose of preparing the directive in the first place.^{326,327} However, others believe that the views of incompetent individuals, with regards to their contemporaneous treatment situation, should be taken into account and weighed against the treatment preferences outlined in their advance directive.³²⁸ In fact, the National Ethics Council in Germany has proposed that incompetent individuals should be allowed to revoke their advance directive to refuse treatment if they exhibit clear signs of a will to live, unless the advance directive contains specific conditions.³²⁹ It could be argued that allowing incompetent individuals to revoke their advance directives could be more feasible for a value statement or a directive containing more general preferences regarding treatment. In such cases, a proxy (if nominated) could also be consulted before a decision is made regarding an incompetent individual's withdrawal of an advance directive.

Storing an Advance Directive

The implementation of an advance directive is dependent on it being accessible when decisions on treatment need to be made for its author. However, given the potential time lag between the time when a directive is drafted and when it is actually required to be implemented, the author of the directive should carefully consider where and with whom the advance directive should be stored. Given the importance of the advance directive, in addition to the author keeping his or her own copy, a copy should also be placed in the individual's medical record, so that it is accessible in any medical situation. This could initially be achieved by a GP keeping a copy of the advance directive in the individual's medical file. Alternatively, if the individual is living in a nursing home or other long-term care facility the directive could be kept on file there. Similarly to their last will and testament, some individuals may wish to store a copy of their advance directive with their solicitor or legal adviser.

326 Michalowski, *op. cit.*

327 Campbell, *op. cit.*

328 Tonelli, *op. cit.*

329 German National Ethics Council, *op. cit.*, p.65: "any signs of a will to live in a person who is no longer mentally competent invalidate the binding character of an advance directive in which treatment is refused, unless: a. the medical decision situation is described in the advance directive in sufficiently concrete terms; b. the advance directive refers to the signs of a will to live mentioned above and stipulates that they shall be immaterial to the decision; c. the advance directive has been drawn up in writing or comparably reliably documented; and d. the drafting of the advance directive has been preceded by appropriate advice."

There are some registries for the storage of advance directives, for example the US Living Will Registry,³³⁰ which electronically stores the advance directives of any individual who has registered through a member healthcare provider.³³¹ Registered individuals increase the likelihood of their advance directive being utilised in a given treatment situation, since all registered advance directives are available to any of the member healthcare providers when required. Individuals can take other measures to ensure their advance directives will be made available and utilised when required, for example, it is recommended that any nominated proxy should also be given a copy of the advance directive as a backup to the version kept in the medical record. While it is optional for individuals to give copies of their advance directive to those close to them, such as their family members, it is advisable to make these individuals aware of the existence of an advance directive.³³² This further highlights the importance of individuals communicating with those close to them throughout the whole process of drafting and implementing their advance directive.

By making more people aware of the existence of an advance directive, there is less chance of an individual being treated without the healthcare professionals first consulting the directive. As noted above, in certain emergency situations it may not always be possible to delay treatment until an advance directive is consulted. However, if the directive is easily accessible it is more likely to be consulted, even in emergencies. When the idea of the advance directive was first proposed it was suggested that individuals should carry their advance directive on their person,³³³ however, as this may not always be practical, others advise individuals to carry some form of card indicating that they have made an advance directive and where a copy could be obtained.^{334, 335, 336}

It is also essential for individuals to ensure that any copy of their advance directive that is in storage corresponds to the most up-to-date version of their directive. Therefore, if a directive has been altered, this new version should be sent to all other parties with a copy of the preceding version, which itself should be destroyed. Otherwise conflicts regarding the correct treatment could arise and individuals could potentially be treated in accordance with an older advance directive that no longer reflects their views and preferences regarding their treatment.³³⁷

330 The US Living Will Registry can be accessed at the following website: <http://www.uslivingwillregistry.com/default.asp>

331 Member healthcare providers can include: hospitals, doctors, skilled nursing facilities, nursing facilities, home health agencies, providers of home health care, ambulatory surgery centres and hospices, all of whom pay a fee to have unlimited access to the registry. However, it is free for any individual to register an advance directive in the system. For further information see: <http://www.uslivingwillregistry.com/howitworksprovider.shtm>

332 British Medical Association, 2000, *op. cit.*, p.9.

333 Kutner, *op. cit.*

334 See the US Living Will Registry: <http://www.uslivingwillregistry.com/walletcard.shtm>

335 Alzheimer Europe 2005b, *op. cit.*, p.11.

336 British Medical Association, 2000, *op. cit.*, p.9.

337 If an advance directive has been revoked, then all existing copies of that directive should be destroyed for the same reasons.

The ICB recommends that an advance directive should be stored safely, but in such a way that it is easily accessible when required. For example, individuals could keep a copy of their directive themselves but also store their directive in a variety of other locations, such as in their medical records either with their GP or another doctor, or in the hospital or nursing home where they are being cared for or treated. Individuals should also keep a copy of their directive with any proxies they have nominated, and even with members of their family and those close to them if they so wish. At the very least, family members and others close to the author of the advance directive should be made aware of its existence. It is important that, in cases where an individual has altered an advance directive, all persons and institutions storing a copy of the advance directive have the most recent, and therefore valid, copy of the directive.

Concluding Comments

It has been proposed that the role of an advance directive is to “stimulate reflection, communication, and exploration of fears and possibilities with physician and family”.³³⁸ Communication regarding advance directives and end-of-life decision-making should not only be considered at the level of the individual drafting an advance directive but also at a general level. There is a need for increased awareness of and education about the issues surrounding advance directives for all concerned, from the general public, to doctors and other healthcare professionals.

Despite substantial interest in and public support for the concept and importance of advance directives,³³⁹ the actual uptake of advance directives is quite low in most countries, for example, in the US figures vary from approximately 20% to 25%,^{340, 341, 342, 343} while in Germany the uptake is between 15% and 18%.³⁴⁴ As previously noted, an Irish Hospice Foundation survey in 2004 suggested that the uptake of advance directives in Ireland was approximately 14%,³⁴⁵ whereas 11% of respondents to the public consultation for this opinion stated that they had made advance directives.³⁴⁶

There are a number of reasons proposed for the lack of uptake of advance directives, such as a generalised reluctance to face death or the lack of public awareness in relation to advance directives and the complexity of the documentation involved.

The measures outlined above regarding the drafting and implementation of advance directives are also applicable to those individuals without advance directives, since they are relevant to medical treatment and care in general, but particularly end-of-life treatment and care. Increased communication and discussion between all parties, *i.e.* individuals, their families and others close to them, doctors, and other healthcare professionals, will not only help to provide an insight into an individual’s preferences regarding future treatment and care. It will also enable all parties to be better prepared for these and other future treatment situations. While advance directives are widely advocated for end-of-life decisions, they should be seen as part of an overall process that aims to adjust and improve the culture of end-of-life treatment and care for all parties concerned.

338 O'Neill, *op. cit.*

339 Donnelly, *op. cit.*, p.65.

340 Fagerlin and Schneider, *op. cit.*

341 Hecht and Shiel, *op. cit.*

342 Crane, MK, Wittink, M and Doukas, DJ 2005. Respecting End-of-Life Treatment Preferences. *American Family Physician* 72 (7): 1263-1268.

343 The President's Council on Bioethics, *op. cit.*, p.71.

344 Personal communication with the German National Ethics Council.

345 Irish Hospice Foundation Survey, *op. cit.*, p.21.

346 See Appendix 1, The Public Consultation.

APPENDICES

Appendix 1:

The Public Consultation

Introduction

In accordance with the policy established at its inception, the Irish Council for Bioethics has carried out a public consultation in connection with its current work on the topic of advance directives. As was the case with previous such exercises, the present consultation has been responded to very positively. The public contributions have aided the ICB to a great degree. This input to the current study is gratefully acknowledged by those engaged on the study and by the ICB itself.

The results of the consultation, each response to which has been individually studied and archived, have been one of the key elements in the preparation of the preceding document and have helped in the development of the views set out in the document. The details of the consultation – its procedures, responses, and assessments, for example – while of undoubted interest to the reader of the document, would not lie easily in the body of the document and are, accordingly, presented in depth in the present Appendix.

Initial Procedures

The initial stage in the consultation was its public announcement in the broadcast and print media in May/June 2006. Details of the channels used are presented in Figure A. A specimen press advertisement is shown in Figure B. Interested members of the public were invited to submit their views by completing a questionnaire, which was available in hard copy from the ICB Secretariat or online at the ICB website.

The design of such a questionnaire is the most important element of a consultation. It must be clear, unambiguous and uncomplicated; it must elicit objectively the views of a respondent; and it must permit the respondent to submit his or her own comments on matters, which it may be felt have not been covered adequately or at all in the questions posed. The ICB decided on a modified version of a questionnaire, which had been published by the British Medical Council. The relevant reference is given at the end of the issued questionnaire, which is presented as Figures C1-C4.

Figure A - Advance Directives: Public Consultation

Advertising:

Irish Times	May 15th
Irish Independent	May 15th
Irish Examiner	May 15th
Metro	May 15th, 16th, and 17th
Link to Age Action Website	

Publicity - Radio:

Newstalk 106 (Damien Kiberd)	May 16th
South East Radio (Ellen Smith)	May 19th
RTÉ (Pat Kenny)	May 24th
Highland Radio (Shaun Doherty)	June 8th

Publicity - Print:

Sunday Tribune	May 21st
Irish Times Health Supplement	June 13th

Figure B.

THE IRISH COUNCIL FOR

BIOETHICS

COMHAIRLE BITHÉITICE NA hÉIREANN

INVITATION TO PARTICIPATE IN A SURVEY
ON ADVANCE DIRECTIVES/LIVING WILLS
FROM THE IRISH COUNCIL FOR BIOETHICS

The Irish Council for Bioethics is considering the ethical and legal issues surrounding advance directives and whether there is a demand or a necessity for advance directives, legally binding or otherwise, in Ireland.

An advance directive/living will is a statement made by a competent adult relating to the type and extent of medical treatments they would or would not want to undergo in the future should they be unable to express their wishes at that time.

In preparing its report the Council wishes to survey public opinion in Ireland on this matter. It therefore invites interested members of the public, professional or voluntary organisations to fill in a questionnaire.

Questionnaires are available from the Irish Council for Bioethics, 19 Dawson Street, Dublin 2 (ph: 01 6380920) and must be returned by 16th June 2006. Submissions can also be made via the Bioethics website, www.bioethics.ie.

Figures C1 – C4.

THE IRISH COUNCIL FOR	Academy House	Tel: 01-6611901	Email: info@bioethics.ie	
BIOETHICS	19 Dawson St.	Fax: 01-6762346	Web: www.bioethics.ie	
COMHAIRLE BITHEITICE NA hÉIREANN	Dublin 2.			

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ADVANCE DIRECTIVE/LIVING WILL SURVEY

An advance directive/living will is a statement made in writing or orally by a competent adult relating to the type and extent of medical treatments they would or would not want to undergo in the future should they be unable to express their wishes at that time. In some cases advance directives can also include a proxy directive, whereby the person who made the directive nominates someone (proxy) to make medical treatment decisions on their behalf should they be unable to express their wishes. **An advance directive is not enforceable if the actions outlined in it are themselves illegal, e.g. request for euthanasia.**

The Irish Council for Bioethics/Comhairle Bitheitice na hÉireann is currently considering the ethical and legal issues surrounding the feasibility, format, content and implementation of advance directives and whether there is a demand or a necessity for advance directives, legally binding or otherwise, in Ireland. In preparing its report the Council wishes to survey public opinion in Ireland on this matter. Please use this form to let us know your views. Responses will be treated as confidential. Extracts of unattributed comments made in section 12 may be quoted in the final report. Thank you for taking the time to respond.

Questionnaires must be returned by 16th June 2006.

Gender	Male	Female				
	<input type="checkbox"/>	<input type="checkbox"/>				
Age Group	16-25	26-35	36-45	46-55	56-65	66+
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Education	Primary	Lwr Secondary*	Upr Secondary†	Third Level		
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
Religious Beliefs	Yes	No				
	<input type="checkbox"/>	<input type="checkbox"/>				
Health Status	Good	Fairly Good	Fairly Poor	Poor		
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		

* Lower Secondary equivalent to Junior Certificate
† Upper Secondary equivalent to Leaving Certificate

- 1. Please indicate if you have encountered any of the following three experiences in the last five years.**

Hospitalisation (yourself)	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Hospitalisation (family member)	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Death of a family member, relative or friend	Yes <input type="checkbox"/>	No <input type="checkbox"/>

- 2. Please indicate if you had ever heard of the words "advance directive" or "living will" before this survey.** (Respond by choosing one of the three answers below).

Yes	<input type="checkbox"/>
Yes, but I was unsure of it's meaning	<input type="checkbox"/>
No	<input type="checkbox"/>

- 3. Have you actually written up an advance directive/living will or any document concerning your future medical care?**

Yes <input type="checkbox"/>	No <input type="checkbox"/>
------------------------------	-----------------------------

- 4. Due to an illness (i.e. stroke, dementia) or accident (i.e. traffic accident), you may become incapable of communicating your decisions. In such a case, do you feel it is better to have expressed your wishes in advance regarding medical treatment?**

Strongly agree	<input type="checkbox"/>
Moderately agree	<input type="checkbox"/>
Moderately disagree	<input type="checkbox"/>
Strongly disagree	<input type="checkbox"/>

For those of who have chosen strongly or moderately agree please answer Questions 5 – 10.

For those of who have chosen moderately or strongly disagree please move onto Question 11.

- 5. Please indicate the reasons why you feel it is better to have expressed your wishes in advance regarding medical treatment.** (You may tick more than one box).

I want to undergo the treatment of my choice	<input type="checkbox"/>
There may be differences in opinions between family members	<input type="checkbox"/>
I do not wish to burden my family with end-of-life decisions	<input type="checkbox"/>
I want to make known my wishes regarding being an organ donor	<input type="checkbox"/>
I want to seriously consider my end-of-life decisions	<input type="checkbox"/>
I do not trust the current medical profession	<input type="checkbox"/>
I want to decide for myself	<input type="checkbox"/>
Other (please elaborate using section 12 of the form)	<input type="checkbox"/>

6. Please indicate what you might like to express in an advance directive.

(You may tick more than one box).

- | | |
|---|--------------------------|
| Treatment related decisions in the case of becoming terminally ill
(e.g. whether or not you wish to receive life-prolonging treatment) | <input type="checkbox"/> |
| Treatment related decisions regarding "pain" during terminal stages
(e.g. whether or not you wish to be treated with painkillers) | <input type="checkbox"/> |
| Whether or not you would like to be informed of your diagnosis/
prognosis (e.g. health information to be directly disclosed to you) | <input type="checkbox"/> |
| Treatment related decisions in the case of long-term coma | <input type="checkbox"/> |
| Whether or not you would like to be artificially ventilated in the terminal
stages of illness | <input type="checkbox"/> |
| Whether or not you would like to be an organ donor for transplantation | <input type="checkbox"/> |
| Whether or not you would like to donate your body for educational purposes | <input type="checkbox"/> |
| End-of-life treatment related decisions (e.g. whether you would
like to die in the hospital) | <input type="checkbox"/> |
| Other <i>(please elaborate using section 12 of the form)</i> | <input type="checkbox"/> |

7. Please indicate how detailed you would like to describe your treatment options when creating an advance directive.

- | | |
|---|--------------------------|
| As detailed as possible (i.e. grant or withhold specific treatments) | <input type="checkbox"/> |
| General preferences (i.e. statement about personal values and
treatment preferences) | <input type="checkbox"/> |
| Other <i>(please elaborate using section 12 of the form)</i> | <input type="checkbox"/> |

8. Supposing you have created an advance directive please indicate to what extent you would like to be treated according to your advance directive.

- | | |
|---|--------------------------|
| My advance directive should be strictly observed | <input type="checkbox"/> |
| As much as possible; yet as long as my reasons are observed,
the advance directive does not need to be strictly observed | <input type="checkbox"/> |
| Just as a reference | <input type="checkbox"/> |

9. Please indicate how you would like to record your advance directive.

- | | |
|---|--------------------------|
| Documented (written document or voice recording) | <input type="checkbox"/> |
| Orally to someone who will act in accordance with your wishes (proxy) | <input type="checkbox"/> |
| A combination of a document and a proxy | <input type="checkbox"/> |

Please return forms to:

Public Consultation/Advance Directive
Irish Council for Bioethics
Academy House
19 Dawson Street, Dublin 2

10. Do you feel such documents need to be legally binding?

Necessary

Unnecessary

4

Do not know

4

11. Please indicate the reasons why you feel it is not better to express your wishes in advance regarding medical treatment. (You may tick more than one box).

My family will make such decisions when the time is needed

My doctor will make such decisions when the time is needed

11

I am currently healthy, there is no need to consider such decisions

9

At my present age, there is no need to consider such decisions

☐

I have no information about advance directives

11

I feel that I will never be in situation where I would need an advance directive

4

It is impossible to think of such decisions for it is impossible to imagine myself in such a situation

11

I do not want to think that I will eventually die or lose my memory

☐

12. Please use this space to express any additional views you may have on advance directives (*additional pages can be used*).

It will be noted that the questions are preceded by an explanatory note, which defines the term advance directive and gives the context for the present study by the ICB. The topic under consideration was likely to be much less familiar to the general public than the subject of previous consultations (e.g. genetically-modified crops and foods). Such probable unfamiliarity would not, however, imply that the topic would not be of interest or possibly even concern to members of the public once they became aware of its implications. Indeed, part of the rationale behind the undertaking of this study by the ICB was the perceived need to create awareness of a subject that has considerable ethical and legal implications.

A second section prefacing the actual questions sought personal (though anonymous) background details of the person responding to the questionnaire. Such information is most useful when the information submitted is being assessed and placed in context. Thanks are due to all who proved the details sought. A final point made was that the responses to the questionnaire would be confidential and unpublished, although extracts of salient comments made by individual respondents might be quoted in the final document..



The Public Response

In all, the ICB received 429 submissions – 67 on questionnaire forms and 362 online. This very satisfactory input by respondents was most gratifying to the members of the Rapporteur Group, not least because of the volume of detailed information provided. The individual submissions were logged and scrutinised by members of the ICB Secretariat, who produced as a working document a detailed statistical analysis of the information received. This document forms the basis of much of the present Appendix.







The Findings Of The Consultation

In the following pages, the findings are presented and discussed under the headings of (a) the prefatory background detail information and (b) the questions posed, taken individually, in order. In regard to (a), an additional item of information is the country of residence of the respondent.





Background Personal Information



Gender		Response Percent	Response Total
Male		32.9%	141
Female		67.1%	288
Statistics based on 429 respondents.			

Female respondents outnumber male by slightly over 2:1.





Age Group		Response Percent	Response Total
16-25		8.2%	35
26-35		31.2%	134
36-45		14.7%	63
46-55		15.6%	67
56-65		16.8%	72
66+		13.5%	58
Statistics based on 429 respondents.			

The number of submissions from persons in the younger age groups is an interesting finding, as it is often assumed that health-related cares are the concerns of the older generations. Submissions from those in the under 35 age groups were almost exclusively submitted online.

Education		Response Percent	Response Total
Primary		1.4%	6
Lwr Secondary (equivalent to Junior Certificate)		3.7%	16
Upr Secondary (equivalent to Leaving Certificate)		13.6%	58
Third Level		81.3	347
Statistics based on 427 respondents.			



Religious Beliefs		Response Percent	Response Total
Yes		65.5%	281
No		34.5%	148

Statistics based on **429** respondents.

Health Status		Response Percent	Response Total
Good		79.2%	339
Fairly Good		17.5%	75
Fairly Poor		1.6%	7
Poor		1.6%	7

Statistics based on **428** respondents.

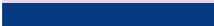


The fact that virtually all respondents enjoy good or fairly good health indicates the perceived relevance of the topic among those without current health problems. It is also, most likely, a good indicator of the latent interest in the subject among those currently aware of it or its implications.

Residence		Response Percent	Response Total
Ireland		96.2%	409
Other		3.8%	16

Statistics based on **425** respondents.

Responses to the Questions posed

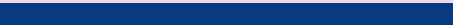


Q 1.

Please indicate if you have encountered any of the following three experiences in the last five years		Response Percent	Response Total
Hospitalisation (yourself)		35.8%	134
Hospitalisation (family member)		62.3%	233
Death of a family member, relative or friend		70.1%	262

Statistics based on **374** respondents.

While it would not be valid to extrapolate from data for a limited number of persons to the public in general, it is nonetheless evident that there are circumstances in which ill-health or mortality have a major collective influence on people’s lives.



Q 2.

Please indicate if you have ever heard of the term “advance directive” or “Living will” before this survey		Response Percent	Response Total
Yes		75.3%	323
Yes but I was unsure of its meaning		14.2%	61
No		10.5%	45

Statistics based on **429** respondents.

Although some 90% of respondents were aware of or understood the terms in question, it must be recognised that the respondents are a self-selecting population with an interest in the topic.





Q 3.

Have you actually written up an advance directive/living will or any document concerning your future medical care?		Response Percent	Response Total
Yes		11.2%	48
No		88.8%	379

Statistics based on **427** respondents.

In 2004, 14% of a representative sample of the Irish public stated they had written an advance directive in a questionnaire commissioned by the Irish Hospice Foundation. In countries such as the US, where there is a legal framework for advance directives, it is estimated that 20-25% of the general public have made an advance directive.

Q 4.

Due to illness (i.e. stroke, dementia) or accident (i.e. traffic accident), you may become incapable of communicating your decisions. In such a case, do you feel it is better to have expressed your wishes in advance regarding medical treatment?		Response Percent	Response Total
Strongly Agree		73.9%	317
Moderately Agree		19.1%	82
Moderately Disagree		1.9%	8
Strongly Disagree		5.1%	22

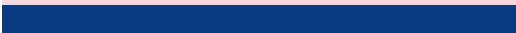








Statistics based on **429** respondents; 0 filtered; 0 skipped

Q 5.

Please indicate the reasons you feel it is better to have expressed your wishes in advance regarding medical treatment. (You may tick more than one box)		Response Percent	Response Total
I want to undergo the treatment of my choice		54.2%	200
There may be differences in the opinions between family members		43.1%	159
I do not wish to burden my family with end-of-life decisions		69.1%	255
I want to make known my wishes regarding being an organ donor		63.4%	234
I want to seriously consider my-end-of life decisions		58.5%	216
I do not trust the current medical profession		13.3%	49
I want to decide myself		63.7%	235
Other (please elaborate in the final section of the form)		6.2%	23
Statistics based on 369 respondents.			

The views indicated are self-explanatory and reflect the principal concerns relevant to actual or potential future health concerns.




Q 6.

Please indicate what you might like to express in an advance directive. (You may tick more than one box)		Response Percent	Response Total
Treatment related decisions in the case of becoming terminally ill (e.g. whether or not you wish to receive life-prolonging treatment)		90%	332
Treatment related decisions regarding "pain" during terminal stages (e.g. whether or not you wish to be treated with painkillers)		67.8%	250
Whether or not you would like to be informed of your diagnosis/prognosis (e.g. health information to be directly disclosed to you)		78.9%	291
Treatment related decisions in the case of long-term coma		83.2%	307
Whether or not you would like to be artificially ventilated in the terminal stages of illness		83.5%	308
Whether or not you would like to be an organ donor for transplantation		75.9%	280
Whether or not you would like to donate your body for educational purposes		49.3%	182
End-of-life treatment related decisions (e.g. whether you would like to die in the hospital)		71.8%	265
Other (please elaborate in the final section of the form)		7%	26

Statistics based on **369** respondents.

The range of subsidiary questions presented under this heading covers the principal factors relevant to an advance directive.

Q 7.

Please indicate in how much detail you would like to describe your treatment options when creating an advance directive.		Response Percent	Response Total
As detailed as possible (e.g. grant or withhold specific treatments)		44.5%	163
General preferences (e.g. statement about personal values and treatment preferences)		52.2%	191
Other (please elaborate in the final section of the form)		3.3%	12

Statistics based on **366** respondents.




The respondents were more or less equally divided in relation to the form an advance directive should take. The specificity of a directive would have implications with respect to the legal validity of the directive.

Q 8.

Supposing you have created an advance directive please indicate to what extent you would like to be treated according to your advance directive?		Response Percent	Response Total
My advance directive should be strictly observed		42.3%	154
As much as possible: yet as long as my reasons are observed, the advance directive does not need to be strictly observed		54.1%	197
Just as a reference		3.6%	13




Statistics based on **364** respondents.

Q 9.

Please indicate how you would like to record your advance directive.		Response Percent	Response Total
Documented (written document or voice recording)		46.3%	171
Orally to someone who will act in accordance with your wishes (a proxy)		6%	22
A combination of a document and a proxy		47.7%	176
Statistics based on 369 respondents.			

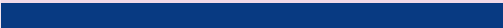







The submissions indicate that over 90% of respondents wish to have their directive recorded in the form of a written document. Half of this group would also like to appoint a proxy to interpret their directive. This may reflect a desire to ensure that the advance directive is complied with.

Q 10.

Do you feel such documents need to be legally binding?		Response Percent	Response Total
Necessary		65.9%	243
Unnecessary		13.3%	49
Do not know		20.9%	77
Statistics based on 369 respondents.			

Two-thirds of respondents stated that an advance directive should be legally binding. The number of uncertain responses is significantly higher than in other cases, which may reflect the general uncertainty surrounding the legality of advance directives.

Q 11.

Please indicate the reasons you feel it is NOT better to express your wishes in advance regarding medical treatment. (You may tick more than one box)		Response Percent	Response Total
My family will make such decisions when the time is needed		88.5%	23
My doctor will make such decisions when the time is needed		50%	13
I am currently healthy, there is no need to consider such decisions		3.8%	1
At my present age , there is no need to consider such decisions		7.7%	2
I have no information about advance directives		7.7%	2
I feel that I will never be in a situation where I will need advance directives		11.5%	3
It is impossible to think of such decisions for it is impossible to imagine myself in such a situation		7.7%	2
I do not want to think that I will eventually die or lose my memory		3.8%	1

Statistics based on **26** respondents.

Q 12.

Please use this space to express any additional views you may have on advance directives		Response Percent	Response Total
			148

Statistics based on **148** respondents.

This heading is presented above merely as the final element of the questionnaire, although it is, of course, a key element of the consultation. Due to the necessarily unique nature of the individual replies, they require separate consideration, which is presented below.

Analysis of the Responses Made Under Question 12

In all, 149 respondents made additional comments, covering a wide range of topics, under question 12. These provided a great deal of valuable information, the salient elements of which are discussed below. The submissions under consideration may be divided for convenience into broad categories. The first relates to advance directives in all their aspects – the philosophy underlying them; their legal status; their period of currency; their implementation; and their implications.

Second are those responses dealing with practical issues and problems, which it is perceived may arise in connection with the drafting and implementation of advance directives. Third, there are a significant number of submissions in which opinions on the medical profession are expressed, and which merit separate consideration. Fourth, there are some respondents who consider that advance directives should cover some issues peripheral to medical treatment, but which are nonetheless relevant.

It should be understood that the above categorisation is arbitrary and has been made for purposes of clarity only. There is no ranking or weighting of the four groups, which manifestly are inter-related, and should be considered as together forming a whole. It is recommended that the reader consider this section in its entirety, because of the interdependence of views categorised under different headings, the designation of which derives largely from the content of the individual submissions.

The Contents of an Advance Directive

The present document has considered in much detail all relevant aspects of advance directives, including their contents and scope. It is not the intention to rehearse these topics here, but as respondents to the survey have expressed their opinions as to the contents of directives, it is important that the subject be dealt with briefly in this Appendix.

Respondents have expressed the views that the contents of an advance directive should include: (a) details of medical treatment to be administered when the patient is incapacitated, (b) a specification of “ownership” of such treatment by the patient, and (c) a description of the treatments that the patient does not want administered. One submission notes that the most significant element of a directive is a refusal of treatment.

Total number of submissions on topic: 4

Life and Death Issues

This heading appears in advance of the detailed presentation on directives, as it touches issues that are fundamental to the very concept of advance directives and their contents. The view was expressed in one submission that death issues were as important as life concerns, and this was reflected in the marked division of opinion among respondents. Some were of the view that patients should die a natural death without medical intervention apart from palliative care, notably relief of pain, that life decisions were in the hand of God alone, and that it was morally and ethically wrong to change God's plan. However, other submissions were emphatic that the right to decide on life or death belonged to the patient.

Total number of submissions on topic: 14

The Legal Status of Advance Directives

Over one-fifth of respondents commented on various aspects of the legal status of advance directives, the clear consensus being that such directives should be legally binding and that there should therefore be legal certainty that the patients' views expressed therein would be implemented. Advance directives should be legally defined without any ambiguity. Individual respondents commented that such directives should not be overridden, by either the patient's next of kin or by a proxy; in the latter case guidance only was considered permissible.

Some of the respondents expressed doubts about the desirability of advance directives being legally binding, though they stated that the wishes contained in advance directives should be followed. At present, both patients and medical professionals were legally vulnerable, in the view of one respondent. (One submission considered that there should be legal protection for healthcare professionals not observing advance directives.) Another expressed doubt that advance directives would be valid in circumstances where the patient was incapacitated, while another submission noted that while legally binding advance directives appeared acceptable, their implementation could still be a matter for the courts.

Only two submissions were expressly opposed to incorporation of advance directives in legislation, and one respondent took the view that legally binding advance directives would be against the Constitution. However, it was apparent from views recorded under other headings that the number of respondents opposed to advance directives having legal force was greater than at first seemed apparent.

Two final views were expressed under the present heading. One raised the question as to whether a patient could forego treatment without having made an advance directive, and the other stated that at present any directive could be open to interpretation and that the law should be definite and "insisted that no medication or treatment could be withheld."

Total number of submissions on topic: 33

Patients' Wishes

The views considered under this heading overlap considerably with some of those expressed elsewhere in the present discussion, but it has been considered useful to summarise in this Appendix the express comments on patients' individual wishes, which lie at the heart of any discussion of advance directives. It should be noted that the total number of submissions on patients' wishes is separate (and additional) to similar totals under other headings.

Several respondents stated that in any consideration of treatment of terminally ill or incapacitated patients, their express views were the deciding factor and should be strictly implemented. While patients' wishes should be expressed to doctors and others, healthcare professionals should not disregard these wishes in order to avoid conflicts with a patient's family. The autonomy or independence of patients should be preserved even when they were incapacitated.

The view was expressed in several further submissions that a patient's life should not be prolonged if the patient was in a vegetative state or if the future quality of a patient's life was likely to be poor. Reference was made in some responses to palliative care, notably the relief of severe pain, which in cases of terminal illness should be the sole form of treatment given.

Total number of submissions on topic: 21

Patients' Rights

Although there is a very close relationship with the heading "Patients' Wishes," it is appropriate, in view of the comments made by respondents, that there should be a separate heading relating to the matter of patients' rights.

The principal perceived rights of patients are the following: (a) the right to consent to or refuse medical treatment(s); (b) the right to make a legal statement of their preferences; (c) the right to decide who should be made aware of a patient's medical condition; and (d) the right to have wishes expressed in regard to organ or body donation, or in regard to transplantation, respected. It may be noted that the aforementioned has proved contentious in families, according to some respondents, with the patient's wishes either being ignored or implemented only with a degree of family dissention. Views in regard to donation are very strongly held by those expressing them.

One final view expressed was that the lives of the vulnerable should be respected in accordance with their wishes, with no other person assuming a power of decision.

Total number of submissions on topic: 11

The Role of The Family

The great majority of responses in favour of the making of advance directives provide as one of the principal reasons for doing so the perceived benefits to the families of patients. The submissions repeatedly take the view that if a family member is incapacitated or terminally ill, members of that family are already under such stress and trauma that they should not be faced with life or death considerations on behalf of a loved one. Further, it is considered that a divergence of opinion within a family in regard to a course of action could lead to tension and, possibly, disputes.

Those supporting advance directives believe that the prior preparation of a directive, with a clear statement of a person's views regarding future medical treatment, would offer considerable relief to family members when grievous ill-health occurs. It has been suggested that a proposed advance directive should be discussed within the family, and that, possibly, there could be counselling and appropriate consultations.

Total number of submissions on topic: 23

Creating or Increasing Public Awareness of Advance Directives

Several respondents considered that the survey was timely and that there was a need for public awareness of the importance or relevance of advance directives. Education on the subject was thought advisable, possibly commencing in the schools. One submission took the view that education and discussion on the topic would best be carried out through the public media, where it would not be influenced by personal circumstances such as a family illness or bereavement.

Total number of submissions on topic: 11

Advice and Guidance in Making an Advance Directive

There was a clear wish among some respondents that advice, guidance and information be provided to assist prospective patients and their families in the making of decisions to be enshrined in an advance directive. It was suggested that detailed information should similarly be available in order that an advance directive would be unambiguous. Several submissions proposed the drawing up of a standard advance directive form or "universal legal template document". It was suggested that any such form be circulated, before issue, to all interested parties for comment. One respondent also recommended guidance for healthcare teams.

Total number of submissions on topic: 10

Perceived Benefits / Importance of Advance Directives

Nearly forty submissions fall under this heading and, again, there is overlap with some views expressed elsewhere in this Appendix; once more, however, the total given below for submissions in this category is a distinct, additional one.

The perceived benefits to patients' families have been discussed separately, but an additional view may be noted, the submission stating that if the patient's family was (or, presumably, was likely to be) around at the time of critical decisions there would be no need for advance directives, but if there was no family presence an advance directive should be made.

Benefits of advance directives as cited in the submissions are the following: (a) advance directives give individuals control over their medical care at a future time when they may be incapable of taking such decisions; (b) legally binding advance directives give healthcare professionals a framework in which to work; (c) advance directives can help reduce shortages of body/organ donors; and (d) an advance directive may remove the indignity of medical resuscitation if further treatment of a patient is likely to be futile.

However, an opposing view is expressed in replies which state (a) that there is never a need for an advance directive and (b) that advance directives have more to do with cost than with ethics, it being cheaper to create a climate in which the old or terminally ill will feel they have fewer rights.

Total number of submissions on topic: 37

The Worth of Advance Directives

A considerable number of respondents made the point that it was practically impossible for the authors of advance directives (unless currently ill) to anticipate their views on future medical treatment. Firstly, the authors could simply change their minds, for whatever reason, and, secondly, nobody could foresee what medical advances might occur in the possibly lengthy period between making the directive and needing medical treatment. The view was expressed that advance directives should be statements of principle, and that they should be time-specific. To definitively specify medical care could, if an advance directive is fully observed, prevent the current best treatment being given.

Although one respondent took a different approach, suggesting that advance directives should be quite detailed in order to cover various future medical situations, the clear consensus was that advance directives should be reviewed and/or updated after a suitable interval in the light of prevailing circumstances. Related observations were that, where uncertainty arose in regard to treatment at a future time when medical advances had been made, it could be claimed that the directive was not based on an "informed decision"; and that a review provision would take account of current medical and family circumstances. One respondent expressed a concern that, if there were a change of mind on the part of an incapacitated patient in the light of events, how would he or she make this known.

Total number of submissions on topic: 23

Attitudes Towards the Medical Profession

Respondents were divided in their views on the medical profession; some expressing unqualified trust, and others equally emphatic distrust. Two submissions noted that advance directives were unnecessary, as healthcare professionals would behave ethically in any event, and, equally, hospitals would have a commitment to preserve life. Others noted that patients would or should trust the medical profession and that some decisions should best be left to healthcare professionals, there being no rational alternative to this. One submission noted that the ultimate decision should be left to doctors and nurses, with advance directives there to guide them (sic) – families were likely to be too emotional to make objective decisions. In practice, decisions were often made in accordance with family, not patient, wishes. A proxy with a documented directive should wield major influence and should decide on a course of action if conflicting opinions arise.

In contrast, two respondents thought that the choice of treatment, where an advance directive existed, should not rest with the medical profession. A further three submissions expressed doubts that medical personnel would abide by an advance directive, with one respondent stating that some professionals have ignored patients' wishes specified in an advance directive. Other respondents stated that healthcare professionals must be guided ethically by an advance directive where one existed, and one respondent commented that a directive should be implemented even if in conflict with the views of the patient's family. Respondents reported cases of nurses' insistence on treatment despite expressed views and of doctors persisting in further tests when the patient was clearly terminally ill.

Total number of submissions on topic: 20

Medical Treatment

Respondents stated that treatment must always benefit the patient. There should be no "heroic treatment" in cases of terminal illness, and there should be no strenuous treatment given to elderly patients. Although one submission stated that doctors should not hasten a patient's death against their wishes, and another posed the question of life support in a case of coma with the possibility of recovery, all responses were opposed to the prolongation of life on the basis of doctors' or family wishes, or where there is no hope of recovery, or in terminal illness.

Total number of submissions on topic: 18

Euthanasia or Legalised Assisted Death

The submissions covered a wide spectrum of opinion, ranging from total opposition to advocacy of voluntary euthanasia as a human right. Most respondents refer specifically to the need for the old and vulnerable to be protected from euthanasia. One submission notes that the experience in countries that permit euthanasia is that directives promote a “culture of death,” and, further, could lead healthcare professionals into regarding vulnerable groups (e.g. elderly without relatives) as “bed-blockers,” and could possibly result in healthcare professionals making decisions leading to the accelerated death of such patients.

Two submissions critical of the present survey, discussed earlier, have expressed fears that euthanasia could be permitted, and another considers that advance directives could assist a “vocal minority” in forcing the country to introduce euthanasia. One respondent notes as “a sad fact” that euthanasia is not even discussed in Ireland. Several submissions take the view that patients who wish to hasten their own death should be free to do so.

Total number of submissions on topic: 25

Detailed Aspects of Advance Directives

While the principal thrust of submissions in regard to advance directives concerned the manner in which patients’ wishes regarding future medical treatment were taken into account, a considerable number raised points of detail, some of which are of paramount importance. The following paragraphs list, and comment on as appropriate, these ancillary considerations, as highlighted by respondents. For convenience, they are dealt with under separate sub-headings.

Patients’ Religious Beliefs

Specific reference was made to the importance of religious beliefs to individual patients and to the need that such beliefs should be respected in any decisions taken. One respondent had membership of a minority religion and had felt vulnerable within the Irish medical system, taking the view that it should not be up to a hospital to take ethical decisions on a patient’s behalf. Another submission stated that medical treatment decisions should not be influenced by a Judaeo-Christian viewpoint.

Total number of submissions on topic: 4

Nomination of Proxies

Several respondents considered the nomination of one or more proxies to act on behalf of a patient incapable of taking a decision on medical treatment. However, there was no clear consensus on the exact role of proxies. One submission noted that proxies should have the right of interpretation and/or decision regarding treatment, depending on the exact circumstances of a case.

Total number of submissions on topic: 4

Competence to make an Advance Directive

Two respondents considered the minimum age of competence for the making of a directive. One noted that this question arose because of the present uncertain legal position of those aged between 16 and 18 years, adding the view that the question should be resolved before directives were introduced. The second stated that the minimum age should be 18 or 21 years. Another submission made the point that persons wishing to make a directive should be deemed fit to do so, lest there be future contention on this point.

Total number of submissions on topic: 3

Donation of Body or Organs for Research or Transplantation

Several submissions highlighted this topic as a key element of advance directives, and as a reason for making directives. Respondents noted cases of family dissention over the express wish in an advance directive to donate, with the patients' wishes being overruled. Such wishes should be respected and the present situation where they can be ignored rectified.

Total number of submissions on topic: 4

Attitudes of Solicitors

Three respondents commented on experience with their solicitors. In one case the solicitor was unaware of the advance directives concept, while in the other two instances there was a refusal either to incorporate the elements of an advance directive in a normal will or even to discuss the concept. In the latter instance, the solicitor's religious beliefs were cited as the reason. It may be added that one respondent, on consulting a doctor on making an advance directive, was informed that the matter would have to go to court

Total number of submissions on topic: 4

Additional Content of Advance Directives

Four respondents expressed the view that advance directives should incorporate patients' views (whether for or against) such matters as memorial service(s) and choice of interment or cremation.

Total number of submissions on topic: 4

Notification of Existence of Advance Directives

Several submissions made the point that if patients had made advance directives it was essential that hospitals and healthcare professionals should be aware of the existence of these directives. Among the suggestions offered were that there should be a formal register of advance directives or, alternatively, a database, which could be readily accessed when required.

Total number of submissions on topic: 4

An Overview of the Above Responses

Although a great deal of valuable opinion was provided by the respondents, who clearly considered their responses carefully, the ICB is aware of the danger of over-reliance on the quantitative results of the survey. This point is elaborated on in the final section of this Appendix. The survey has been very worthwhile as a qualitative exercise, in that it has highlighted all the obvious, as well as many latent considerations, which might be expected to apply to advance directives. Further, it is always helpful when respondents express their opinions in their own words and at their chosen length. This helps to eliminate "second-guessing" of the views of the public, as the submissions are wholly authentic.

Conclusion

Some 429 people responded to the public consultation, providing the ICB with a considerable body of valuable information. However, while the detailed data constituted an important input to the current study, it must be borne in mind that the information was submitted by a narrow sector of the public. The findings, therefore, should not be extrapolated to cover a greater range of public opinion.

Further, it would appear that the number of respondents indicating experiences of hospitalisation or mortality (cf. Question 1 above) was rather higher than would have been expected. This is not to devalue the data in question, but rather to confirm that the implications of the survey responses for a wider population sector cannot be gauged. However, while the data may be circumscribed in this regard, they are of particular value in that they derive from actual, recent situations rather than potential future circumstances.

It has been noted above that the great majority of respondents were at least aware of the concept of an advance directive, and that many of them expressed clear views as to their future wishes in regard to health problems. It also emerged from the submissions, however, that despite the relevance of the topic to many respondents, and their awareness of it, few had taken any action in this regard.

The overall picture is that the respondents in general have positive views as to the relevance and importance of the advance directive concept, and have advanced several cogent reasons for this, as well outlining a range of views regarding possible courses of action. However, it is also apparent that, despite the generally informed nature of submissions, there is a need for further information and, possibly, guidance in regard to taking positive steps concerning advance directives.

It is hoped that the present document will create an appropriate general awareness of a health-related topic that, despite its apparently great lack of current recognition, will become increasingly relevant to people's lives, especially as the options for medical treatment grow in line with advances in technology.

Acknowledgements

The ICB is greatly indebted to all the respondents to the survey, both for the views expressed and the related information provided. This has considerably helped the ICB in its deliberations.

Grateful acknowledgement is made to Dr. Paddy Flanagan, who compiled this Appendix, and to the ICB Secretariat – Dr. Siobhan O'Sullivan (Scientific Director), Ms. Emily de Grae, Dr. Stephanie Dyke and Mr. Paul Ivory – for processing the submissions and for preparing the analysis on which this Appendix is based.

Appendix 2:

Submissions Sought by the Irish Council for Bioethics

Age Action Ireland
An Bord Altranais
Bar Council
Church of Ireland General Synod
Mr. John Costello (E.F. Collins Solicitors)
Humanist Association of Ireland
Irish Association for Palliative Care
Irish Bishops' Committee for Bioethics
Irish College of General Practitioners
Irish Hospice Foundation
Irish Hospital Consultants Association
Irish Medical Organisation
Irish Patients' Association
Islamic Cultural Centre of Ireland
Jewish Ireland
Law Reform Commission
Law Society of Ireland
Medical Council
Mental Health Commission
Mental Health Ireland
Methodist Church in Ireland
National Council on Ageing and Older People
Nationaler Ethikrat (German National Ethics Council)
Dr. Shaun O'Keeffe (Dept. of Geriatric Medicine, Merlin Park Regional Hospital, Galway)
Ombudsman for Children
Professor Desmond O'Neill (Dept. of Medical Gerontology, Trinity Centre for Health Sciences)
Presbyterian Church in Ireland
Wards of Court Office
Watch Tower Bible and Tract Society of Ireland

Appendix 3:

Submissions Received by the Irish Council for Bioethics

The following is a list of the oral and/or written submissions received by the Irish Council for Bioethics.

A&L Goodbody Solicitors
An Bord Altranais
Bar Council
Church of Ireland General Synod
Mr. John Costello (E.F. Collins Solicitors)
Humanist Association of Ireland
Irish Bishops' Committee for Bioethics
Irish Hospice Foundation
Irish Hospital Consultants Association
Irish Patients' Association
Jewish Ireland
Law Reform Commission
Living Earth
Medical Council
Mental Health Commission
Methodist Church in Ireland
National Council on Ageing and Older People
Nationaler Ethikrat (German National Ethics Council)
Dr. Shaun O'Keeffe (Dept. of Geriatric Medicine, Merlin Park Regional Hospital, Galway)
Professor Desmond O'Neill (Dept. of Medical Gerontology, Trinity Centre for Health Sciences)
Presbyterian Church in Ireland
Watch Tower Bible and Tract Society of Ireland

Appendix 4:

Sample Advance Directive Forms

Sample 1

Advance Statement Made Under The Mental Health (Care And Treatment) (Scotland) Act 2003¹

Name of person making this statement: _____

Address of person making this statement: _____

I _____ [name] wish the following views to be taken into account, in the event of decisions about my care and treatment being made under the Mental Health (Care and Treatment) (Scotland) Act 2003, and my being unable to express my views about my care and treatment at that time.

1. I would like to receive the following treatments:

2. I would **not** like to receive the following treatments:

3 Signature _____

¹ Reproduced with the kind permission of the Scottish Executive. Available from the following website:
<http://www.scotland.gov.uk/Resource/Doc/26350/0012826.pdf>

4. Witness Certificate² (please see note at bottom of page)

I certify that in my opinion _____ [*insert name of person making advance statement*]
has the capacity of properly intending the wishes set out above.

I hereby witness his/her signature.

[signature]

[date of witnessing signature]

Full name of witness: _____

Address of witness: _____

Designation of witness: _____

[Occupation/category which enables the witness to act as a 'prescribed person']

You should keep a list of the names of everyone who has a copy of this document.

² Those who can witness an Advance Statement are: a clinical psychologist entered on the British Psychological Society's register of chartered psychologists, a medical practitioner, an occupational therapist registered with the Health Professions Council, a person employed in the provision of (or in managing the provision of) a care service, a registered nurse, a social worker and a solicitor.

Sample 2

Withdrawal Of Advance Statement Made Under The Mental Health (Care And Treatment) (Scotland) Act 2003³

Name of person withdrawing advance statement: _____

Address of person withdrawing advance statement: _____

I _____ [name] wish to withdraw my advance statement, which was signed and dated on _____ [date witnessed] and which was witnessed by _____ [name of witness].

1. Signature _____

2. Witness Certificate⁴

I certify that in my opinion _____ [name of person withdrawing advance statement] has the capacity of properly intending the wishes set out above.

I hereby witness his/her signature.

_____ [signature] _____ [date of witnessing signature]

Full name of witness: _____

Address of witness: _____

Designation of witness: _____

[Occupation/category which enables the witness to act as a 'prescribed person']

³ Reproduced with the kind permission of the Scottish Executive. Available from the following website:
<http://www.scotland.gov.uk/Resource/Doc/26350/0012826.pdf>

⁴ Those who can witness an Advance Statement are: a clinical psychologist entered on the British Psychological Society's register of chartered psychologists, a medical practitioner, an occupational therapist registered with the Health Professions Council, a person employed in the provision of (or in managing the provision of) a care service, a registered nurse, a social worker and a solicitor.

Sample 3

Advance Directive For Health Care⁵

Name: _____

Address: _____

Hospital Unit Number: _____

It is my express wish that if I should develop:

- a) senile, severe degenerative brain disease (due to Alzheimer's disease, arterial disease, AIDS, or other agency or
- b) serious brain damage resulting from accidental or other injury or illness or
- c) advanced or terminal malignant disease or
- d) severely incapacitating and progressive degenerative disease of the nerves or muscles

and have become mentally incompetent to express my opinion about accepting or declining life sustaining treatment, and if two independent physicians conclude that, to the best of current medical knowledge, my condition is irreversible then the following points should be taken into consideration:

- In the event of a cardiac arrest, regardless of the cause, I should not be given cardiopulmonary resuscitation.
- Any separate illness – for example, pneumonia or a heart or kidney condition – that may threaten my life should not be given active treatment unless it appears to be causing me undue physical suffering.
- During such an advanced illness, if I should become unable to swallow food, fluid, or medication then these should not be given by any artificial means except to relieve obvious suffering.
- During such an illness, if my condition deteriorates without reversible cause, and as a result my behaviour becomes violent, noisy, or in other ways degrading, or if I appear to be suffering severe pain, then any such symptoms should be controlled with suitable drug treatment, regardless of the consequences on my physical health and my survival, within the extent of the law.
- Other requests.

⁵ Reproduced with the kind permission of the New Zealand Medical Association. Available from the following website:
<http://www.nzma.org.nz/patient-guide/advance-directive.pdf>

The object of this directive is to minimise distress or indignity which I may suffer or create during an incurable illness, and to spare my medical advisers or relatives, or both, the burden of making difficult decisions on my behalf.

Signed _____ Date _____

Witness 1 _____

Witness 2 _____

Statement by one witness: I _____ declare that in my

opinion the above person _____ is of sound mind and understands the meaning and implications of this directive.

Signed _____ Date _____

Sample 4

Advance Directive⁶

I _____
of _____

advise that in any circumstance that I am not competent to make a choice about a future healthcare procedure, should the following situation arise:

that I accept/decline/withdraw (delete those which are not applicable) the following treatment/s

I confirm that information about the risks, consequences and treatment options of my decision were given (summarise below):

Name of usual doctor (or Medical Practitioner with the closest relationship with the patient)

Signed _____ (Patient)

Signed _____ (Doctor)

Witnessed _____ (Contact Person)

Date _____

Updated/reconsidered/endorsed on _____

Updated/reconsidered/endorsed on _____

Updated/reconsidered/endorsed on _____

⁶ Reproduced with the kind permission of the New Zealand Medical Association. Available from the following website:
<http://www.nzma.org.nz/patient-guide/advance-directive.pdf>

Sample 5

Health Care Proxy⁷

(General Laws of Massachusetts, Chapter 201D)

EXPLANATION

You have the right to give instructions about your own health care. You also have the right to name someone else to make health-care decisions for you. This form lets you do either or both of these things. It also lets you express your wishes regarding anatomical gifts and the designation of your primary physician. If you use this form, you may complete or modify all or any part of it.

Part 1 of this form is a Designation of Health Care Agent. Part 1 lets you name another individual as Agent to make health-care decisions for you if you become incapable of making your own decisions. You may also name an alternate Agent to act for you if your first choice is not willing, able or reasonably available to make decisions for you. Unless related to you by blood or marriage, you may not appoint a person who is an operator, administrator or employee of a “facility” as defined in Chapter 111: Section 70E of the General Laws of Massachusetts’s as your health care Agent if, at the time of executing the Health Care Proxy, you are a patient or resident of such facility or have applied for admission to such facility.

Your Agent may make all health-care decisions for you, including, absent a limitation by you, decisions concerning providing, withholding or withdrawing of a life-sustaining procedure. Unless you limit the Agent’s authority, your Agent will have the right to:

- (a) Consent or refuse consent to any care, treatment, service or procedure to maintain, diagnose or otherwise affect a physical or mental condition unless it’s a life-sustaining procedure or otherwise required by law.
- (b) Select or discharge health-care providers and health-care institutions;
- (c) Consent or refuse consent to life-sustaining procedures, such as, but not limited to, cardiopulmonary resuscitation and orders not to resuscitate.
- (d) Direct the providing, withholding or withdrawal of artificial nutrition and hydration and all other forms of health care.

⁷ Reproduced with the kind permission of USLegalForms.com. Available from the following website: <http://www.uslegalforms.com>

Part 2 of this form lets you give specific instructions about any aspect of your health care. Choices are provided for you to express your wishes regarding the provision, withholding or withdrawal of treatment to keep you alive, including the provision of artificial nutrition and hydration as well as the provision of pain relief. Space is also provided for you to add to the choices you have made or for you to write out any additional instructions for other than end of life decisions.

Part 3 of this form lets you express an intention to donate your bodily organs and tissues following your death.

Part 4 of this form lets you designate a physician to have primary responsibility for your health care.

After completing this form, sign and date the form at the end. **It is required that 2 other individuals sign as witnesses.** You should give a copy of the signed and completed form to your physician, to any other health-care providers you may have, to any health-care institution at which you are receiving care and to any person(s) you name as your Health Care Agent. You should talk to the person(s) you have named as your Agent to make sure that your wishes are understood and that the person(s) is willing to take the responsibility of having your Health Care Proxy.

You may revoke a health care Agent by notifying your Health Care Agent or your health-care provider orally or in writing or by any other act evidencing a specific intent to revoke the Health Care Proxy. You may replace this form at any time.

SAMPLE

Part 1: Designation of Health Care Agent

(1) DESIGNATION OF AGENT:

I designate the following individual as my Agent to make health-care decisions for me:

(name of individual you choose as Agent)

(address)

(home phone)

(work phone)

OPTIONAL: If I revoke my Agent's authority or if my Agent is not willing, able, or reasonably available to make a health-care decision for me, I designate as my first alternate Agent:

(name of individual you choose as first alternate Agent)

(address)

(home phone)

(work phone)

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

(name of individual you choose as second alternate Agent)

(address)

(home phone)

(work phone)

(2) AGENT'S AUTHORITY:

My Agent is authorized to make all health-care decisions for me, except as I state here:

(Add additional sheets if necessary.)

(3) WHEN AGENT'S AUTHORITY BECOMES EFFECTIVE:

My Agent's authority becomes effective when my primary physician determines I lack the capacity to make my own health-care decisions. As to decisions concerning the providing, withholding and withdrawal of life-sustaining procedures my Agent's authority becomes effective when my primary physician determines I lack the capacity to make my own health-care decisions and my primary physician and another physician determine I am in a terminal condition or permanently unconscious.

(4) AGENT'S OBLIGATION:

My Agent shall make health-care decisions for me in accordance with this power of attorney for health care, any instructions I give in Part 2 of this form, and my other wishes to the extent known to my Agent. To the extent my wishes are unknown, my Agent shall make health-care decisions for me in accordance with what my Agent determines to be in my best interest. In determining my best interest, my Agent shall consider my personal values to the extent known to my Agent.

(5) NOMINATION OF GUARDIAN:

If a guardian of my person needs to be appointed for me by a court, (please check one):

☐ I nominate the Agent(s) whom I named in this form in the order designated to act as guardian.

☐ I nominate the following to be guardian in the order designated:

☐ I do not nominate anyone to be guardian.

Part 2: Instructions for Health Care

If you are satisfied to allow your Agent to determine what is best for you in making end-of-life decisions, you need not fill out this part of the form. If you do fill out this part of the form, you may strike any wording you do not want.

(6) END-OF-LIFE DECISIONS:

I direct that my health-care providers and others involved in my care provide, withhold, or withdraw treatment in accordance with the choice I have marked below:

Choice Not To Prolong Life

I do not want my life to be prolonged if: (please check all that apply)

(i) I have a terminal condition (an incurable condition caused by injury, disease, or illness which, to a reasonable degree of medical certainty, makes death imminent and from which, despite the application of life-sustaining procedures, there can be no recovery)

and

regarding artificial nutrition and hydration, I make the following specific directions:

	I want used	I do not want used
Artificial nutrition through a conduit	<input type="checkbox"/>	<input type="checkbox"/>
Hydration through a conduit	<input type="checkbox"/>	<input type="checkbox"/>

(ii) I become permanently unconscious (a medical condition that has been diagnosed in accordance with currently accepted medical standards that has lasted at least 4 weeks and with reasonable medical certainty as total and irreversible loss of consciousness and capacity for interaction with the environment. The term includes, without limitation, a persistent vegetative state or irreversible coma)

and

regarding artificial nutrition and hydration, I make the following specific directions:

	I want used	I do not want used
Artificial nutrition through a conduit	<input type="checkbox"/>	<input type="checkbox"/>
Hydration through a conduit	<input type="checkbox"/>	<input type="checkbox"/>

Choice To Prolong Life

- ☐ I want my life to be prolonged as long as possible within the limits of generally accepted health-care standards.

RELIEF FROM PAIN: Except as I state in the following space, I direct treatment for alleviation of pain or discomfort be provided at all times, even if it hastens my death:

(7) OTHER MEDICAL INSTRUCTIONS:

(If you do not agree with any of the optional choices above and wish to write your own, or if you wish to add to the instructions you have given above, you may do so here.) I direct that:

(Add additional sheets if necessary.)

Part 3: Anatomical Gifts at Death

(OPTIONAL)

(8) I am mentally competent and 18 years or more of age.

I hereby make this anatomical gift to take effect upon my death. The marks in the appropriate squares and words filled into the blanks below indicate my desires.

I give:

- ☐ my body;
- ☐ any needed organs or parts;
- ☐ the following organs or parts;

To the following person or institutions

- ☐ the physician in attendance at my death;
- ☐ the hospital in which I die;
- ☐ the following named physician, hospital, storage bank or other medical institution;

- ☐ the following individual for treatment;

for the following purposes:

- ☐ any purpose authorized by law;
- ☐ transplantation;
- ☐ therapy;
- ☐ research;
- ☐ medical education.

Part 4: Primary Physician

(OPTIONAL)

- (9) I designate the following physician as my primary physician:

(name of physician)

(address)

(phone)

OPTIONAL: If the physician I have designated above is not willing, able or reasonably available to act as my primary physician, I designate the following physician as my primary physician:

(name of physician)

(address)

(phone)

Primary Physician shall mean a physician designated by an individual or the individual's Agent or guardian, to have primary responsibility for the individual's health care or, in the absence of a designation or if the designated physician is not reasonably available, a physician who undertakes the responsibility.

- (10) **EFFECT OF COPY:** A copy of this form has the same effect as the original.

- (11) **SIGNATURE:** Sign and date the form here:

I understand the purpose and effect of this document.

Date: _____

Sign Your Name _____

Print Your Name: _____

(address): _____

(12) SIGNATURES OF WITNESSES:

Statement Of Witnesses

SIGNED AND DECLARED by the above-named declarant as and for his/her written Health Care Proxy pursuant to the General Laws of Massachusetts, Chapter 210D, who in his/her presence, at his/her request, and in the presence of each other, have hereunto subscribed our names as witnesses, and state and affirm:

That the Principal appeared to be at least eighteen years of age, of sound mind and under no constraint or undue influence. Further, neither witness is named as a Health Care Agent in this Health Care Proxy.

First witness:

(print name)

(address)

(signature of witness)

(date)

Second witness:

(print name)

(address)

(signature of witness)

(date)

Rapporteur Group on Advance Directives

Dr. Peter McKenna

Rotunda Hospital

Mr. Asim A. Sheikh, BL

Division of Legal Medicine, University College Dublin

Professor David Smith

Royal College of Surgeons in Ireland

Terms of Reference

1. To determine if there is a demand or a necessity for advance directives, legally binding or otherwise, in Ireland.
2. To consider the legal and ethical issues surrounding the feasibility, format, content and implementation of advance directives.
3. To seek the views of stakeholders and the general public on issues relating to advance directives.
4. To produce a report/an opinion detailing all aspects of the Council's deliberations and conclusions on advance directives.

The Irish Council for Bioethics

Comhairle Bitheitice na hÉireann

Mr. Dermot Gleeson, SC, Chairman

Dr. Alan Donnelly, Department of Physical Education and Sport Sciences, University of Limerick

Dr. Dolores Dooley, Philosopher and Lecturer in Bioethics

Professor Andrew Green, School of Medicine and Medical Science, University College Dublin; National Centre for Medical Genetics, Our Lady's Hospital for Sick Children

Professor Linda Hogan, Irish School of Ecumenics, Trinity College Dublin

Dr. Richard Hull, Department of Philosophy, National University of Ireland Galway

Dr. Peter McKenna, Rotunda Hospital

Professor J.V. McLoughlin, Department of Physiology, Trinity College Dublin

Mr. Stephen McMahon, Irish Patients' Association

Professor Cliona O'Farrelly, School of Medicine and Medical Science, University College Dublin; Education and Research Centre, St Vincent's University Hospital

Dr. Darina O'Flanagan, National Disease Surveillance Centre

Professor Richard O'Kennedy, School of Biotechnology, Dublin City University

Mr. Asim A. Sheikh, BL, Division of Legal Medicine, University College Dublin

Professor David Smith, Royal College of Surgeons in Ireland

Secretariat

Dr. Siobhán O'Sullivan

Ms. Emily de Grae

Dr. Stephanie Dyke

Mr. Paul Ivory

Terms of Reference

1. To identify and interpret the ethical questions raised by biomedicine in order to respond to, and anticipate, questions of substantive concern.
2. To investigate and report on such questions in the interests of promoting public understanding, informed discussion and education.
3. In light of the outcome of its work, to stimulate discussion through conferences, workshops, lectures, published reports and where appropriate to suggest guidelines.

List of Abbreviations

*Abbreviations are explained at their first occurrence in the text.
They are also shown below for convenient reference.*

ANH	Artificial Nutrition and Hydration
BMA	British Medical Association
CPR	Cardiopulmonary Resuscitation
GMC	General Medical Council
GP	General Practitioner
IHF	Irish Hospice Foundation
ICB	Irish Council for Bioethics
LRC	Law Reform Commission
PSDA	Patient Self-Determination Act
PVS	Persistent Vegetative State
TNS MRBI	Taylor Nelson Sofres Market Research Board of Ireland
UK	United Kingdom
US	United States

List of Legal Cases

Republic of Ireland

In the matter of a Ward of Court (withholding medical treatment) (No. 2) [1996] 2 I.R. 79.
J.M. v The Board of Management of St. Vincent's Hospital [2002] 1 I.R. 321.

International

Airedale N.H.S. Trust v Bland [1993] A.C. 2 W.L.R. 316.
Burke, R (on the application of) v General Medical Council & Ors [2005] EWCA Civ 1003.
Cruzan v Director Missouri Department of Health [1990] 497 U.S. 261.
HE v A Hospital N.H.S. Trust [2003] 2 FLR.
In re Quinlan [1976] 355 A. 2d. 647.
Re C (adult: refusal of medical treatment) [1994] 1 All E.R. 819.
Re T (adult: refusal of medical treatment) [1992] 4 All E.R. 649.
Re W (a minor)(medical treatment) [1992] 4 All E.R. 627.

List of Statutory Instruments

Republic of Ireland

Bunreacht na hÉireann, Constitution of Ireland, 1937

Non-Fatal Offences Against the Person Act, 1997

Powers of Attorney Act, 1996

Courts (Supplemental Provisions) Act, 1961

International

Act on the Status and Rights of Patients, 1992

Adults with Incapacity (Scotland) Act, 2000

Austrian Federal Hospital Law, 1957

California Natural Death Act, 1976

Federal Act on Living Wills [Patientenverfügungs-Gesetz], 2006

Law on Patients' Legal Status, 1998

Medical Treatment Contracts Act (WGBÖ), 1994

Mental Capacity Act, 2005

Patient Self-Determination Act (PSDA), 1990

Termination of Life on Request and Assistance with Suicide (Review Procedures) Act, 2002

Glossary

Note that the terms listed are explained as they apply in the context of the present document. In broader, more general use some of the terms will have wider meaning.⁸

Advance Care Planning

A process of planning future medical care by discussions and team building between healthcare professionals, patients and families, aimed at preserving quality of care at the end of life.

Advance Healthcare Directive

An advance healthcare directive is 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 if unable to express consent or dissent at that time. Also known as an advance directive.

Advance Statement

See *Advance Healthcare Directive* above.

Artificial Nutrition and Hydration (ANH)

Techniques such as the use of nasogastric (nasal), gastrostomy (stomach) or intravenous tubes, or subcutaneous hydration to provide a patient with nutrition and hydration where that patient cannot take food or fluids orally.

Assisted Suicide

Where an individual suffering from an incurable illness or chronic intense pain intentionally takes his or her own life with the help of another individual. In the case of physician-assisted suicide, the doctor does not directly cause the patient's death but enables the patient to choose the time and circumstances of his or her own death.

Autonomy

An individual's ability to make independent choices regarding consent to or refusal of medical treatment without any external influences.

"Best Interests" Standard

Where no clear treatment preferences can be determined for an incompetent individual, the court weighs the benefits and burdens of a particular treatment before making a decision on behalf of that individual based on what a "reasonable person" would decide in the same situation.

Capacity

An individual's ability to make a decision regarding medical treatment and care based on that individual's use, understanding and retention of the information provided to him or her.

⁸ Several definitions were derived from: <http://encyclopedia.thefreedictionary.com/>, and <http://www.thefreedictionary.com/>

Cardiopulmonary Resuscitation (CPR)

Restoration of cardiac output and pulmonary ventilation by artificial respiration and closed-chest massage after cardiac arrest and apnoea.

Competence

See *Capacity* above.

Conscientious Objection

The decision of a doctor or other healthcare professional, based on his or her moral and/or religious principles, not to accede to a patient's treatment wishes.

Consent

An individual's agreement to accept or undergo a particular medical treatment or medical procedure.

Durable Power of Attorney for Healthcare

A legal document in which competent individuals nominate someone to act as their representative and make medical treatment and healthcare decisions on their behalf should they become incapacitated at some time in the future.

Enduring Power of Attorney

A legal document in which competent individuals nominate someone to make certain personal care decisions on their behalf should they become incapacitated at some time in the future. However, currently in Ireland, an enduring power of attorney does not cover decisions on medical treatment or surgery.

Euthanasia

The act or practice of a doctor ending the life of an individual, suffering from a terminal or incurable illness, as painlessly as possible, with that individual's consent *e.g.* as by lethal injection.

Futile

In healthcare terms, futility refers to a medical treatment or procedure that is considered to offer a low probability of success in the current medical circumstances.

Healthcare Proxy

A form of advance directive, whereby the author of the directive nominates someone (the proxy) to be involved in the healthcare decision-making process on his or her behalf should the author become unable to express his or her wishes.

Heroic Measures

Extreme emergency measures to prolong a patient's life where the patient would otherwise not survive.

Imprescriptible Right

A right that cannot in any circumstances be legally taken away or abandoned.

Life-Sustaining Treatment

A medical treatment that is considered essential to keep an individual alive, *e.g.* cardiopulmonary resuscitation, or artificial ventilation.

Living Will

A written advance healthcare directive.

Natural Death

When the death of an individual results from the normal progress of a disease or illness. Any medical treatment received at this juncture would be palliative rather than curative.

Palliative Care

Care that improves the quality of life of patients and their families facing a life-threatening illness, through the prevention and relief of pain and other symptoms of the illness, including physical, psychosocial and spiritual problems, without affecting a cure.

***Parens Patriae* Jurisdiction**

The legal authority of the courts to make medical or other decisions on behalf of a child or incompetent adult based on the best interests of the individual involved.

Persistent Vegetative State (PVS)

This is a medical condition in which the brain stem remains alive and functioning while the cortex of the brain loses its function and activity. The PVS patient is usually considered to be unconscious and unaware. He or she is capable of reflex movement, particularly in response to painful stimuli, but is incapable of voluntary movement and can feel no pain. The patient can breathe unaided and digestion continues to function, but he or she has no cognitive brain function and cannot communicate in anyway. Also known as permanent vegetative state.

Proxy

Someone nominated by the author of a healthcare proxy to be involved in the healthcare decision-making process on the author's behalf should he or she become unable to express his/her wishes. The proxy can make a healthcare decision based solely on his or her judgment of what the author would want in that situation. Alternatively, the proxy could interpret for the members of the healthcare team the author's wishes regarding healthcare in a given situation, as set out in an advance directive.

Self-Determination

See *Autonomy* above.

Substituted Judgment Standard

A legal standard of decision-making on behalf of an incompetent individual that seeks to make healthcare decisions by trying to determine what the individual would decide in the current situation if capable of doing so.

Ward of Court

An individual who by reason of incapacity, through minority or mental illness, is under the protection of a court either directly or through a guardian appointed by the court. The court has the final authority to make any decisions, medical or otherwise, on behalf of such an individual.

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