



LAW REFORM
COMMISSION/COIMISIÚN UM
ATHCHÓIRIÚ AN DLÍ

REPORT

BIOETHICS: ADVANCE CARE DIRECTIVES

(LRC 94 – 2009)



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Law Reform Commission

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Full responsibility for this publication lies, however, with the Commission.

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INTRODUCTION

A Background to the Report

1. This Report forms part of the Commission's *Third Programme of Law Reform 2008-2014*,¹ and involves an examination of whether a legislative framework should be put in place for advance care directives. The Report follows the publication in 2008 of the Commission's *Consultation Paper on Advance Care Directives*,² which contained provisional recommendations on the subject. In the Commission's 2006 *Report on Vulnerable Adults and the Law*³ the issue of advance care directives had been briefly discussed in the wider context of reform of the law on mental capacity, but the Commission indicated that it deserved separate treatment and analysis. Thus, the proposals on advance care directives in this Report involve an important aspect of the interaction between law and bioethics and also form an element of the proposed reform of the law on mental capacity.⁴ As the Government's *Scheme of a Mental Capacity Bill 2008* largely proposes to implement the recommendations in the Commission's 2006 Report, the Scheme of the 2008 Bill is referred to in some detail in this Report.

2. The Commission's 2008 Consultation Paper was published to coincide with the Commission's Annual Stakeholder Conference, held on 14 October 2008. The Conference heard from a variety of speakers on the issues raised by the Consultation Paper and the wider health care setting in which advance care directives should be considered.⁵ The Conference delegates

¹ *Report on the Third Programme of Law Reform 2008–2014* (LRC 86–2007), Project 30.

² *Consultation Paper on Bioethics: Advance Care Directives* (LRC CP 51-2008), available at www.lawreform.ie. This is referred to as the Consultation Paper in the remainder of this Report.

³ LRC 82-2006. The 2006 Report was prepared under the Commission's *Second Programme of Law Reform 2000-2007*

⁴ See paragraphs 1.07-1.09, below.

⁵ The Conference speakers included: Dr Katherine Froggatt (Institute of Health Research, Lancaster University, England), Dr Mary Keys (School of Law, NUI Galway), Dr Doiminic Ó Brannagáin (Consultant Physician in Palliative Medicine), Prof David Smith (Irish Council for Bioethics) and Mr Mervyn Taylor (Hospice Friendly Hospitals). The Conference was opened by Máire Hctor, TD, Minister of State, Department of Health and Children. The Conference was chaired by the

contributed valuable insights into the legal, ethical and practical issues that arise in this area, and the Commission is extremely grateful to them for their assistance in this respect.

3. Since the publication of the Consultation Paper, the Commission received many detailed submissions on its content and these have informed the Commission's analysis in preparing this Report. The Commission also held a series of additional consultative meetings with relevant organisations and individuals in the first half of 2009. This Report sets out the Commission's final recommendations on advance care directives, together with a draft *Mental Capacity (Advance Care Directives) Bill* intended to implement those recommendations.

B Terminology

4. In the Consultation Paper and in this Report, the Commission has used the term "advance care directive" to describe the advance expression of wishes by a person, at a time when they have the capacity to express their wishes, about certain treatment that might arise at a future time when they no longer have capacity to express their wishes (because, for example, of the effects of Alzheimer's disease, coma or stroke). A brief explanation of this is appropriate.⁶ The Commission is aware that there is no single, universal, term in use to describe this advance expression of wishes. Thus, the term "living will" was used in the United States in the late 1960s when they were first popularised. Since then, a number of terms have been used, such as "advance decision", "advance directive," "advance care directive," "advance healthcare directive," "instruction directive," "advance treatment directive" and "advance statement."⁷

5. In preparing this Report, the Commission has considered the appropriate term to be used in this respect. The term "living will" is likely to be thought of as a formal, written, document and as the Commission considers that this would be unduly restrictive in terms of scope, it would not be a suitable term to use. In Europe, it appears that the term "advance directive" is quite often

Commission President, and Commissioner Patricia Rickard-Clarke delivered a presentation setting out the main elements of the Consultation Paper.

⁶ See also the Consultation Paper, paragraphs 1.12-1.18.

⁷ See Irish Council for Bioethics *Is It Time for Advanced Healthcare Directives?* (2007), at1, available at www.bioethics.ie.

used,⁸ and the Commission has therefore concluded that this would, in general, be a suitable expression. The Commission notes that the word “directive” can denote a legally enforceable statement, though allowing some degree of flexibility as to how it is implemented.⁹ The Commission accepts that the word “directive” may appear somewhat formal (as opposed to, for example, “statement”) but has concluded that it has the benefit of indicating an element of enforceability while at the same time indicating a degree of flexibility.

6. The Commission has also concluded that the term “advance directive” might not fully express the health care context within which the expression of wishes arises. For that reason, the Commission has concluded that some reference to the health care setting should be incorporated into the term to be used. While the term “advance healthcare directive” has some attractions in this respect, the Commission considers that, having regard to the wider care setting within which the expression of wishes may arise, such as a hospice care context, the term “advance care directive” appears to be the most suitable term to use. For these reasons, the Commission uses that terms in this Report and also recommends that it be used in the context of any legislative framework involving the advance expression of wishes of an individual in a health care or wider care setting.

7. *The Commission recommends that the term “advance care directive” be used in any legislative framework that deals with the advance expression of wishes of an individual in a health care or wider care setting.*

C Outline of this Report

8. The Commission now turns to outline the main elements of this Report and its recommendations for reform.

1.01 In Chapter 1, the Commission describes the origins and emergence of advance care directives, in the context of advances in health care and the move towards informed decision making. The Commission places this in the wider setting of reform of the law on mental capacity, notably through the Government’s *Scheme of a Mental Capacity Bill 2008*. The Commission also gives some examples of advance care directives to emphasise that they are not confined to the end-of-life setting. The Commission discusses the emergence of

⁸ See, for example, the Council of Europe’s 2009 *Draft Recommendation on Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity*, discussed in Chapter 1, below.

⁹ Thus, Article 249 of the EC Treaty states that an EU Directive “shall be binding, as to the result to be achieved, upon each Member State to which it is addressed, but shall leave to the national authorities the choice of form and methods.”

advance care directives in the United States and the United Kingdom and the growing emergence of relevant international instruments, in particular from the Council of Europe.

9. The Commission also discusses the emergence of the debate on advance care directives in Ireland, including relevant case law and the important work of bodies such as the Irish Council for Bioethics and the Irish Hospice Foundation. The Commission concludes by recommending the introduction of a legislative framework for advance care directives. In this respect, the Commission notes that its recommendations are based on the clear view that the proposed legislative framework is intended to be facilitative, and is aimed at encouraging the use of advance care directives in the wider context of health care planning.

10. The Commission emphasises that its proposals do not affect any action that is currently prohibited by the criminal law, and that they are applicable to refusals of medical treatment and do not extend to treatment requests. The Chapter also sets out the general rights and principles that form the basis for the Commission's detailed proposals in this Report.

11. In Chapter 2, the Commission discusses how third parties, often called health care proxies, may be involved in the decision-making process on which a person has expressed his or her wishes in the advance care directive. The Commission also discusses the relationship between the role of the health care proxy and that of two other separate but related third parties: the personal guardian envisaged in the Government's *Scheme of a Mental Capacity Bill 2008*; and an attorney appointed under the *Powers of Attorney Act 1996*.

12. In Chapter 3, the Commission discusses the main elements of the Commission's proposed legislative framework, including how it would deal with issues such as basic care and life-sustaining treatment. The Commission also sets out the detailed requirements to be in place for an advance care directive to be enforceable, notably whether the advance care directive has been validly made and is applicable to the treatment that is to be given or continued. The Commission concludes by discussing the scope of a proposed statutory Code of Practice on Advance Care Directives that would support the proposed legislative framework.

13. In Chapter 4, the Commission discusses the legal effect of the proposed legislative framework. The Commission refers to the general law on civil and criminal liability that will remain unaffected by its proposals. The Commission then discusses the protections that should be in place for those who follow and implement a valid advance care directive, and what should be the legal position where an advance care directive is not followed. The conclusions reached are predicated on the Commission's clear view that the proposed legislative framework is intended to facilitate and encourage the use

of advance care directives, while also ensuring that they are followed and implemented to the greatest extent possible.

14. Chapter 5 is a summary of the recommendations in the Report.

15. The Appendix to the Report contains a draft *Mental Capacity (Advance Care Directives) Bill 2009*, intended to give effect to the Commission's detailed recommendations for a legislative framework.

CHAPTER 1 ORIGINS OF ADVANCE CARE DIRECTIVES, SCOPE OF REPORT AND GENERAL PRINCIPLES

A Introduction

1.02 In this chapter the Commission describes the origins of advance care directives, the wider setting of the law on mental capacity within which they arise and the general principles that have informed the Commission's approach to this area. In Part B, the Commission discusses the emergence of advance care directives in the context of advances in health care and the move towards informed decision making. The Commission places this in the wider setting of reform of the law on mental capacity envisaged in the Government's *Scheme of a Mental Capacity Bill 2008*. The Commission also provides some examples of advance care directives to emphasise that they are not confined to the end-of-life setting. In Part C, the Commission discusses the emergence of advance care directives in the United States and the United Kingdom, largely associated with a number of high-profile court cases involving end-of-life treatment. The growing emergence of relevant international instruments, in particular from the Council of Europe, is also discussed.

1.03 The Commission then discusses the emergence of the debate on advance care directives in Ireland, including relevant case law and the important work of bodies such as the Irish Council for Bioethics and the Irish Hospice Foundation. The Commission concludes by recommending the introduction of a legislative framework for advance care directives. Part D discusses the scope of this Report, in particular that its focus is on refusals of medical treatment. This Part also points out that the Commission's proposals do not affect any action that is currently prohibited by the criminal law. Part E sets out the general rights and principles that form the basis for the Commission's detailed proposals, derived from the discussion in Part C.

B Emergence of advance care directives

1.04 In this Part, the Commission discusses the emergence of advance care directives. This begins with a discussion of advances in health care and medical treatment and the movement from paternalism in medicine towards a

social model involving informed decision making. The Commission also discusses the connection between advance care directives and the wider setting of reform of the law on mental capacity, notably through the Government's *Scheme of a Mental Capacity Bill 2008*, which derives from the Commission's 2006 *Report on Vulnerable Adults and the Law*. The Commission concludes this Part with some examples of advance care directives.

(1) *Advances in health care, informed decision making and reform of the law on mental capacity*

1.05 The extensive discussion nationally and internationally about advance care directives has arisen against the background of two major developments in health care and treatment, namely, advances in technology and a movement towards the view that patients have the right to make informed decisions about their treatment.

1.06 Regarding the first development, the great advances in medical treatment and technology from the second half of the 20th Century to the present have meant that, in developed countries, people live longer, including those with a serious illness or disease. These advances have also meant that life can be sustained in situations where, previously, nature would have "taken its course" and a person would have died. There is no questioning the positive benefits that these developments have brought, and that future developments may bring cures for illnesses and diseases that are currently terminal. At the same time, developments has made death and dying more complicated. In some instances these developments have led some to fear that they may not be given relevant treatment or, conversely, may be kept alive indefinitely by life-prolonging treatment after they have lost their ability (their mental capacity) to decide on their treatment options and to make their own views known.¹

1.07 The need for advance decision-making initially arose, therefore, because of the complex legal and ethical difficulties that arise where, for example, it is being decided whether to withhold or withdraw artificial nutrition and hydration (ANH) from a particular person who is unconscious or in a coma, in the absence of a clear advance indication about his or her wishes on the matter. In the case of withholding ANH, health care professionals and others - often family members - have to act as substitute decision makers about whether the individual would have wished to have their life sustained, and if so for how long, or would have wished not to be resuscitated. Equally, in the case of withdrawal of ANH, the health care professionals and family members who act as substitute decision makers are faced with deciding whether continuing with artificial intervention is appropriate.

¹ Morgan Capron "Advance Directives" in Kulise and Sige (eds) *A Companion to Bioethics* (1998) at 262.

1.08 The second major development in health care treatment in recent decades has involved the movement towards the view that patients have the right to make informed decisions about their treatment. This involves a significant shift from a paternalistic approach that decisions about health care options and treatment were primarily for health care professionals towards the view that the patient must be actively engaged in a process that leads to informed decision making about care and treatment options. The Commission has previously supported this important development in its *Report on Vulnerable Adults and the Law*,² and contained the *Scheme of a Mental Capacity Bill* that included a general presumption of capacity and a requirement that the assessment of capacity should be based on a functional approach, that is, whether the person understands the decision being considered, including health care decisions, at the time it is being made.

1.09 The Commission also recommended that the current Wards of Court system, administered primarily under the *Lunacy Regulation (Ireland) Act 1871* should be replaced because it is based on the paternalistic approach to capacity and involves the complete removal of decision-making capacity from an individual and the operation of an extreme substitute decision making process under the control of the High Court. The Commission recommended that a new form of decision making process, involving an appointed Personal Guardian to be supervised by a standard-setting Office of Public Guardian, should be put in place. The Personal Guardian would act as an assisting decision maker in conjunction with the individual involved where this remained possible, and would only become a substitute decision maker where it is clear that the individual no longer has any functional capacity. This graduated approach to the assessment of capacity-loss, and the involvement in decision making of a third party Personal Guardian or proxy, is consistent with the maximisation of informed decision making.

1.10 The Commission very much welcomes that this approach has been incorporated into the Government's *Scheme of a Mental Capacity Bill 2008* which was published in September 2008.³ The enactment of such legislation would also fulfil the State's general international obligations under, for example,

² LRC 83-2006.

³ Available at www.justice.ie

the 2006 UN *Convention on the Rights of Persons with Disabilities*⁴ and relevant Council of Europe standards.⁵

1.11 The Commission's 2006 *Report on Vulnerable Adults and the Law* is predicated on the view that the presumption of capacity, and the functional assessment of capacity, is required to support informed decision making. The Commission also acknowledged that the specific issue of how this approach would apply in the context of advance care directives needed further consideration. The Commission noted that, at that time, the Irish Council for Bioethics had begun work on this area and that it would be appropriate to postpone further analysis in that light.⁶ As discussed in Part C below, the Council published an Opinion on this matter in 2007 and the Commission also received submissions during 2007 indicating that this was an area suitable for inclusion in the Commission's *Third Programme of Law Reform 2008-2014*. As is apparent from the detailed discussion in Part C, below, it is important to emphasise that any proposals on advance care directives should be seen in the context of reform of the law on mental capacity generally, because of the close linkage between issues such as capacity, consent to treatment, refusal of treatment and the appointment of proxies or attorneys by a person with capacity to represent their views in the event of their incapacity.

(2) Examples of advance care directives

1.12 While much of the literature on advance care directives centres around the end-of-life setting (because many of the high-profile cases have involved end-of-life decisions) the Commission emphasises that advance care directives are not confined to this setting. Examples of advance care directives that have arisen in practice include:

- Refusal of blood transfusions⁷
- Refusal of a leg amputation⁸

⁴ See *Report on Vulnerable Adults and the Law* (LRC 83-2006), paragraphs 1.45-1.48.

⁵ See the discussion in paragraph 1.33, below, of the Council of Europe's 2009 *Draft Recommendation on Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity*.

⁶ *Report on Vulnerable Adults and the Law* (LRC 83-2006), paragraph 3.36.

⁷ See *Fitzpatrick v FK* [2006] IEHC 392, [2008] 1 ILRM 68 and *Fitzpatrick v FK (No 2)* [2008] IEHC 104, discussed at paragraphs 1.49-1.55, below.

⁸ See *Re C* [1994] 1 WLR 290 (in which the patient who refused the amputation survived), discussed at paragraph 1.29, below.

- Refusal of treatments by pregnant women⁹
- Refusal of treatment or procedures which may affect a woman's fertility¹⁰
- Do Not Resuscitate (DNR) Orders
- Withdrawal of all life-sustaining treatment.¹¹

1.13 Thus, advance care directives apply in a number of settings: in the context of continuing care for those with chronic medical conditions which are not life-threatening; for those who wish to refuse certain treatments in a specific setting, such as pregnancy; and for those who wish to express their views in an end-of-life context. While end-of-life settings for advance care directives are most likely to produce the most debate and discussion – and requirements for close regulation – advance care directives can also arise in a continuing-life setting also.

C The development of the law on advance care directives

1.14 In this Part, the Commission discusses the emergence of advance care directives in other States, notably the United States and the United Kingdom, largely associated with a number of high-profile court cases involving end-of-life treatment. The Commission then addresses the emergence of international instruments in this area, notably the Council of Europe's 2009 *Draft Recommendation on Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity*, which seeks to build on the 1997 *Convention on Human Rights and Biomedicine* and a 1999 *Recommendation on Mental Capacity*. The Commission then discusses the emergence of the debate on advance care directives in Ireland from the 1980s, which has also developed by reference to a number of high-profile end-of-life cases.

1.15 In 1967, in response to the advances in medical science already mentioned, Luis Kutner, a US attorney, drafted the first "living will." It was intended to serve a number of purposes. First, it was intended to take the burden of making end of life decisions from physicians and relatives. Second, a living will enabled a person to become part of the decision making process, even after they had lost capacity or, perhaps, merely the ability to communicate.

⁹ *Re T (adult: refusal of medical treatment)* [1992] 4 All ER 649.

¹⁰ Code of Practice for *Mental Capacity Act 2005*, at paragraph 9.7.

¹¹ See *Re AK* [2001] 1 FLR 129, at paragraph 1.30.

Third, the existence of living wills helped educate medical professionals that life-prolonging treatment is not always preferable.¹²

1.16 As already noted, the Commission's *Report on Vulnerable Adults and the Law*¹³ supports a presumption of capacity and a functional approach to determining capacity. This is based, in turn, on the view that decision-making should remain for as long as possible in the hands of the individual involved, that assisted decision making (through a Personal Guardian) should be the next step, and that substitute decision making should be postponed for as long as possible. The Commission recognises that this approach is based on the acceptance that substituted decision-making may be flawed,¹⁴ because the decisions of the substitute decision-maker may not reflect the views of the individual but rather the personal opinions of the substitute.¹⁵ This has, in turn, also contributed to the growth in support for the advanced expression of a patient's views.

(1) Developments in the United States

(a) Quinlan case

1.17 Support for advance care directives (or "living wills" as they are commonly called in the United States) grew in the aftermath of a number of court decisions that involved the withdrawal of life support treatment. In 1976, in *Re Quinlan*¹⁶ the father of Karen Ann Quinlan, a 22 year-old woman who was in a persistent vegetative state, applied for an order to discontinue "all extraordinary medical treatment" for her. He argued that the withdrawal of treatment was what his daughter would have wanted had she been able to express her wishes. Her physicians had refused to turn off her artificial respirator, fearing that ending treatment might involve criminal liability and would be contrary to medical ethical practice and standards. The New Jersey Supreme Court held that the State's undoubted interest in preserving life "weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims. Ultimately there comes a point at which the individual's rights overcome the state interest. It is for that reason that

¹² Morgan Capron "Advance Directives" in Kulise and Sige (eds) *A Companion to Bioethics* (1998), at 263.

¹³ LRC 83-2006.

¹⁴ Vig, Taylor, Starks, Hopley, Fryer-Edwards "Beyond Substituted Judgment: How Surrogates Navigate End-Of-Life Decision-Making" (2006) 54 (11) *Journal of the American Geriatrics Society* 1688.

¹⁵ *Ibid.*

¹⁶ 355 A.2d 647 (1976).

we believe Karen’s choice, if she were competent to make it, would be vindicated by the law.” On that basis, the Court held that her death would not be caused by the withdrawal of artificial respiration but by her illness and, on that basis, made the order sought.

(b) Legislative developments

1.18 The *Quinlan* case highlighted the absence of legislation on advance care directives. Within months, the first advance care directive legislation was enacted by the Californian legislature,¹⁷ with other states following this lead. In 1985 the US Uniform Law Commissioners¹⁸ drafted the *Uniform Rights of the Terminally Ill Act*, which was amended in 1989. The purpose of the Act was to provide means by which a person could set out their preferences with regard to life-sustaining medical treatment.¹⁹ It also sought to provide a consistent approach to end-of-life decision-making.²⁰ The Uniform Law Commissioners, acknowledged, however, that the scope of the Act was narrow as it was limited to patients suffering from a terminal illness.²¹

(c) Cruzan v Director of Missouri Department of Health

1.19 Over a decade after the *Quinlan* case, the decision of the US Supreme Court in *Cruzan v Director of Missouri Department of Health*²² led to a second generation of legislation on this issue. In that case, the family of Nancy Cruzan, who was in a persistent vegetative state, applied for a court order to withdraw life-sustaining medical treatment based on an earlier conversation in which Ms Cruzan had stated she did not wish to live if she would face life as a ‘vegetable’. The case involved the application of the Missouri *Uniform Rights of the Terminally Ill Act*, which was based on the 1985 *Uniform Rights of the Terminally Ill Act*.

1.20 In *Cruzan* the US Supreme Court held that competent persons have a “constitutionally protected liberty interest in refusing unwanted medical

¹⁷ *Natural Death Act 1976* (Cal).

¹⁸ The National Conference of Commissioners on Uniform State Laws (NCCUSL), established in 1892, comprises over 300 lawyers appointed by each US state government to research, draft and promote the enactment of uniform state laws in areas where uniformity as between each state in the US federal system is desirable and practical. See generally www.nccusl.org

¹⁹ *Uniform Rights of the Terminally Ill Act 1985*, at 1.

²⁰ *Ibid.*

²¹ *Ibid.*

²² 497 US 261 (1990).

treatment.”²³ This has been interpreted as implicitly establishing “the right to engage in advance planning for incapacity.”²⁴ But the Supreme Court also held that states could insist in their legislation on “clear and convincing evidence” of a patient’s wishes before permitting hospitals to withdraw life support, as Missouri had done in its *Uniform Rights of the Terminally Ill Act*. The Supreme Court noted that written instructions – such as those provided in a living will – are persuasive evidence of an individual’s “prior expressed wishes” regarding medical treatment but that the “informal, casual statements her friends and family remembered” would be insufficient.²⁵ On that basis, the Court in *Cruzan* refused to order the withdrawal of life-sustaining medical treatment.

(d) Further legislative developments

1.21 In the aftermath of *Cruzan*, the United States Federal Congress enacted the *Patient Self-Determination Act 1990*, which partially addressed the problem of educating both patients and doctors. It required health-care institutions receiving federal funds to inform patients of their right to refuse life-sustaining treatments and to complete advance care directives. The 1990 Act also states that if a person has an advance directive, it must be recorded in that person’s medical records.

1.22 End-of-life cases in the United States continue to provoke public debate and controversy. The most high-profile in recent years involved Terri Schiavo, a Florida woman who, having suffered a cardiac collapse at her home in 1990, was later diagnosed as being in a PVS condition. In 1998, her husband Michael Schiavo applied to the Florida courts to have her feeding tube removed. The application was opposed by Terri Schiavo’s family, and this led to extended litigation in the State and federal courts, as well as legislative interventions at State and federal level. Ultimately, in 2005, a Florida court made a final order to remove the feeding tube and Terri Schiavo died shortly after this.²⁶

(2) Developments in the UK

1.23 A similar pattern concerning advance care directives emerged in the United Kingdom, beginning with a number of cases and culminating in legislation enacted in 2005, the *Mental Capacity Act 2005*, which implemented a

²³ 497 US 261 (1990), at 278.

²⁴ Gallagher “Advance Directives for Psychiatric Care: A Theoretical and Practical Overview for Legal Professionals” (1998) 4 Psychol Pub Pol’y & L 746 at 796.

²⁵ *Ibid*, at 266-268.

²⁶ See generally Caplan, McCartney, Sisti (ed), *The Case of Terri Schiavo: Ethics at the End of Life* (2006).

1995 English Law Commission Report that responded to the high-profile *Bland* end-of-life case.

(a) *Airedale NHS Trust v Bland*

1.24 *Airedale NHS Trust v Bland*²⁷ involved Tony Bland who, as a 17 year old, was severely injured in the 1989 Hillsborough football disaster, in which 96 people died in a crush of people at Sheffield Wednesday's Hillsborough stadium before the 1989 FA Cup semi final. The injuries led to profound brain damage, leaving him in a persistent vegetative state (PVS). He was not able to see, hear, taste, smell, speak or communicate in any way, was incapable of involuntary movement, could not feel pain and had no cognitive function. He was able to breathe unaided but as he could not eat or swallow food, he was kept alive on a life support system involving a nasogastric (ng) tube, a feeding tube inserted through the nasal passage and reaching into the stomach.²⁸

1.25 The unanimous view of all the medical team treating Mr Bland was that he had no hope whatsoever of recovery or improvement of any kind. Just over 3 years after he received the injuries, his consultant, supported by other medical experts, reached the conclusion that it would be appropriate to cease further treatment, that the artificial feeding through the nasogastric tube should be withdrawn and that no antibiotic treatment should be given if he developed an infection. The effect would be that, within 2 to 3 weeks he would die by starvation. The NHS Trust treating Mr Bland applied for a declaration that the withdrawal of artificial nutrition and hydration (ANH) in these circumstances would be lawful and that the only treatment required after this would be the sole purpose of enabling him to allow him to end his life and die peacefully with the greatest dignity and the least pain, suffering and distress. The application was supported by his parents and family.

1.26 The House of Lords decided that a doctor treating a patient who did not have the capacity to decide whether or not to consent to treatment was not under an absolute obligation to prolong the patient's life regardless of the circumstances or the quality of the patient's life. The Court held that the test to be applied was whether it was in the patient's best interests not to prolong life because treatment would confer no benefit on him. On that basis, if a responsible and competent doctor made the decision to discontinue treatment, no criminal offence would be involved. Thus the House of Lords agreed that the declaration that had been applied for could be made.

²⁷ [1993] 1 All ER 821.

²⁸ This is to be contrasted with a second form of feeding tube, the percutaneous endoscopic gastrostomy (PEG) tube, which is inserted directly through the stomach wall.

1.27 Two of the Law Lords also expressed views on the potential legal status of advance care directives. Lord Keith stated:²⁹

“an adult, who is conscious and of sound mind...is completely at liberty to decline to undergo treatment, even if the result of his doing so is that he will die. This extends to the situation where the person, in anticipation of his... entering into a condition such as PVS, gives clear instructions that in such event his is not to be given medical care, including artificial feeding, designed to keep him alive.”

1.28 Similarly, Lord Goff stated:³⁰

“a patient of sound mind may, if properly informed, require that life support should be discontinued: see *Nancy B v Hotel-Dieu de Quebec*.³¹ Moreover, the same principle applies where the patient’s refusal to give his consent has been expressed at an earlier date... though in such circumstances especial care may be necessary to ensure that the prior refusal of consent is still properly to be regarded as applicable in the circumstances which have subsequently occurred (see eg *Re T (adult: refusal of medical treatment)*.³²”

(b) Case law after Bland

1.29 In *Re C*,³³ a 68-year old man with chronic paranoid schizophrenia suffered from the delusion that he was a world famous doctor who had never lost a patient. He developed gangrene in his leg, but refused amputation despite the hospital’s assessment that he would die immediately if the operation was delayed. He sought an injunction to prevent the hospital from amputating his leg in the future. Thorpe J was prepared to find him competent and granted the injunction. Mr C survived without the amputation. *Re C* is an illustration that advance care directives are not confined to end-of-life situations but also involve the continuation of care.

1.30 In *Re AK*,³⁴ a 19-year old patient suffered from a progressive neuro-muscular disease causing paralysis. He informed his carers, by means of an eyelid movement, that he would wish his artificial ventilation to be stopped if he could no longer communicate. The health authority applied to the High Court for

²⁹ [1993] 1 All ER 821, at 860.

³⁰ *Ibid*, at 866.

³¹ (1992) 86 DLR (4th) 385 (Quebec Superior Court).

³² [1992] 4 All ER 649.

³³ [1994] 1 WLR 290.

³⁴ [2001] 1 FLR 129.

a declaration that it would be lawful, in accordance with AK's wishes, to discontinue artificial ventilation, nutrition and hydration, two weeks after AK lost all ability to communicate. Hughes J, in granting the declaration, confirmed the "vital nature of the principle of autonomy" and had "no doubt" of AK's capacity, and the validity and applicability of the directive.³⁵

1.31 While both *Re C* and *Re AK* were decided prior to the enactment of the English *Mental Capacity Act 2005*, the decisions indicate the willingness of the English judiciary to uphold valid and applicable advance care directives.

(c) Legislative developments: Mental Capacity Act 2005

1.32 In the aftermath of the *Bland* case, the Law Commission for England and Wales proposed, in the context of a review of mental capacity law (comparable to this Commission's 2006 *Report on Vulnerable Adults and the Law*) that an "advance refusal of treatment" should have legal standing.³⁶ This was implemented in the English *Mental Capacity Act 2005*. The 2005 Act is accompanied by a Code of Practice, which is in line with the recommendations of the Law Commission. The Commission returns to the detailed contents of the English 2005 Act and Code of Practice in Chapter 3.

(3) Developments in the Council of Europe

1.33 Ireland was a founding member of the Council of Europe in 1949, which was established to promote human rights in Europe in the aftermath of World War II. The Council's most well known human rights document is the 1950 *Convention for the Protection of Human Rights and Fundamental Freedoms* (often referred to as the European Convention on Human Rights). The *European Convention on Human Rights Act 2003* incorporated into Irish law (subject to the Constitution) the rights contained in the 1950 Convention. In addition to the 1950 Convention, the Council of Europe has developed a number of specific Conventions³⁷ and Recommendations³⁸ that have an effect

³⁵ [2001] 1 FLR 129, at 136.

³⁶ Law Commission for England and Wales *Report on Mental Incapacity* (No 231 1995) at paragraph 5.16.

³⁷ A Council of Europe Convention, such as the 1950 *Convention for the Protection of Human Rights and Fundamental Freedoms*, only has legal force in Ireland after it has been signed and ratified by the State and enacted by the Oireachtas, as was done by the *European Convention on Human Rights Act 2003*.

³⁸ A Council of Europe Recommendation, while not having the status of a Convention, is binding on the State as a member of the Council of Europe, but it does not form part of Irish law. The Committee of Ministers of the Council of

on this Report. The Council of Europe 1997 *Convention on Human Rights and Biomedicine* deals with the protection of people from the misuse of biological or medical advances. Article 9 of the 1997 Convention is of relevance to this Report as it states:

“The previously expressed wishes relating to medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account.”

1.34 The Council of Europe has also been engaged in the development of a Committee of Ministers Recommendation on two related issues of direct relevance to this Report, Continuing Powers of Attorney (in Ireland, called Enduring Powers of Attorney) and Advance Directives. This would build on the Committee of Ministers’ 1999 *Recommendation on Principles Concerning the Legal Protection of Incapable Adults*, which recommended that legislation for those with incapacity should maximise the preservation of capacity and involve the least interference with the individual’s autonomy. In its 2006 *Report on Vulnerable Adults and the Law*, the Commission supported the adoption of the principles in the 1999 Recommendation, in particular by including them in the general principles underpinning the draft *Scheme of a Mental Capacity Bill* attached to the 2006 Report.³⁹ These principles have also been included in the Government’s *Scheme of a Mental Capacity Bill 2008*,⁴⁰ which proposes to implement the 2006 Report.

1.35 In April 2009, the Council of Europe’s Committee of Experts on Family Law published a *Draft Recommendation on Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity*,⁴¹ which was forwarded to the Committee of Ministers for final approval. The draft Recommendation refers with approval to the 1999 *Recommendation on Principles Concerning the Legal Protection of Incapable Adults* and notes that legislation in Council of Europe member states concerning adults with incapacity promotes autonomy and self-determination. The draft Recommendation also refers in this respect to the requirements to promote autonomy in the 2006 UN *Convention on the Rights of Persons with*

Europe monitors the extent to which a Recommendation has been implemented in a member state.

³⁹ See *Report on Vulnerable Adults and the Law* (LRC 83-2006), paragraphs 2.28 and 2.99; and section 4 of the draft *Scheme of a Mental Capacity and Guardianship Bill* (Report Appendix, p.170).

⁴⁰ Head 1 of the *Scheme of a Mental Capacity Bill 2008*, available at www.justice.ie

⁴¹ Available at www.coe.int

Disabilities.⁴² The draft Recommendation also notes that where member states have enacted legislation on continuing powers of attorney and advance directives (such as the English *Mental Capacity Act 2005* and the other examples discussed below), increasing numbers of adults of all ages are making use of them. The draft Recommendation ends by proposing that member states “promote self-determination for capable adults by introducing legislation on continuing powers of attorney and advance directives or by amending existing legislation, with a view to implementing the principles contained in the appendix to this [draft] recommendation.”

1.36 The draft Recommendation proposes that member states “should promote self-determination for capable adults in the event of their future incapacity, by means of continuing powers of attorney and advance directives” (Principle 1). The draft Recommendation suggests that an advance care directive be defined as “instructions or wishes issued by a capable adult concerning issues that may arise in the event of his or her incapacity” (Principle 2). The draft Recommendation suggests that advance care directives may apply to health, welfare and personal matters, to economic and financial matters, and to the choice of a guardian, should one be appointed (Principle 14). As to legal effect in general, it recommends that States should decide to what extent advance care directives should have binding effect; and that advance directives which do not have binding effect should be treated as statements of wishes to be given due respect. The draft Recommendation also provides that States should address the issue of situations that arise in the event of a substantial change in circumstances (Principle 15).

1.37 As to the form of an advance care directive, the draft Recommendation proposes that member states should “consider whether advance directives or certain types of advance directives shall be made or recorded in writing if intended to have binding effect.” States should also consider what other provisions and mechanisms may be required to ensure the validity and effectiveness of those advance directives (Principle 16). The draft Recommendation provides that an advance directive should be revocable “at any time and without any formalities” (Principle 17).

1.38 The Commission understands at the time of writing (September 2009) that the draft Recommendation is likely to be adopted by the Committee

⁴² In its *Report on Vulnerable Adults and the Law* (LRC 83-2006), paragraphs 1.45-1.48, the Commission noted that a new legislative framework on mental capacity in Ireland was required to meet the State’s obligations under the 2006 Convention. The Government’s *Scheme of a Mental Capacity Bill 2008*, which proposes to implement the Commission’s 2006 Report, would achieve this general objective.

of Ministers of the Council of Europe by the end of 2009 or early 2010.⁴³ While it is not yet, therefore, a final Recommendation, the Commission considers that the work leading up to the publication of the draft Recommendation indicates a growing consensus in the Council of Europe about the need to facilitate the use of advance care directives. In that respect, the principles in the draft Recommendation are of great assistance in the context of the consideration of any proposed legislation in Ireland. It is also notable that the draft Recommendation also deals with continuing (enduring) powers of attorney, a topic dealt with by the Commission in its 2006 *Report on Vulnerable Adults and the Law*, which made proposals on the reform of the law on mental capacity. This inclusion indicates that advance care directives should be considered in the wider context of legislation that deals, or proposes to deal, with mental capacity.

(4) Legislation in Council of Europe Member States

1.39 As the draft Recommendation indicates, many Council of Europe member states have enacted legislation covering advance care directives. In addition to the English *Mental Capacity Act 2005*, the Commission notes that legislation had been enacted in this area in at least 20 Council of Europe member states by 2008.⁴⁴ For example, in Finland, article 8 of the *Act on the Status and Rights of Patients 1992* states that a person must not be given treatment which they have previously refused. In the Netherlands, Article 450 of the Medical Contract provides for a written advance care directive.⁴⁵ In Chapter 3, the Commission considers in detail these and other legislative models from around the world.⁴⁶

⁴³ Information supplied to the Commission by the Secretariat of the Committee of Experts on Family Law (CJ-FA) of the Council of Europe.

⁴⁴ See Alzheimer Europe, *Advance Directives: Summary of the Legal Provisions Relating to Advance Directives per Country* (May 2005), available at www.alzheimer-europe.org, Irish Council for Bioethics *Is It Time for Advanced Healthcare Directives?* (2007), p.5, available at www.bioethics.ie, and *Report of the 4th meeting in 2008 of the Committee of Experts on Family Law (Working Party on Incapable Adults)* (December 2008), available at www.coe.int.

⁴⁵ Nys “Emerging Legislation in Europe on the Legal Status of Advance Directives and Medical Decision-Making with Respect to an Incompetent Patient (‘Living Wills’)” (1997) 4 *European Journal of Health Law* 179 at 184.

⁴⁶ These include the *Medical Treatment Act 1994* (Australian Capital Territory), the *Advance Medical Directive Act 1996* (Singapore) and the *Health Care Directives and Substitute Health Care Decision Makers Act 1997* (Canada).

(5) The development of advance care directives in Ireland

1.40 Developments in Ireland have followed a similar pattern as other States, with the first significant discussion of the issue being a lecture by Costello J in 1986 that addressed the US *Quinlan* case of 10 years previously. In 1996, the High Court and Supreme Court dealt with a high-profile case involving a woman who had been in a near PVS state for over 20 years. The development of a strong hospice movement in Ireland in recent years has also raised the profile of advance care planning at the end of life; and, in 2007 the Irish Council for Bioethics published an Opinion on Advance Care Directives.⁴⁷

(a) Costello J's 1986 lecture on the terminally ill

1.41 In a lecture given in 1986 on the law concerning the terminally ill,⁴⁸ Costello J noted that, in *Re Quinlan*,⁴⁹ the New Jersey Supreme Court had concluded that the withdrawal of artificial respiration from Karen Quinlan would not amount to homicide on the basis that her death had not been as a result of the withdrawal of life-support but had resulted from natural causes. He also suggested that the right of the terminally ill patient to forego life-sustaining treatment is compatible with the provisions of the Constitution of Ireland:⁵⁰

“...there are very powerful arguments to suggest that the dignity and autonomy of the human person (as constitutionally predicated) require the State to recognise that decisions relating to life and death are, generally speaking, ones in which a competent adult should be free to make without outside restraint, and that this freedom should be regarded as an aspect of the right to privacy which should be protected as a ‘personal’ right by Article 40.3 [of the Constitution of Ireland]... [I]n the case of the terminally ill, it is very difficult to see what circumstances would justify the interference with a decision by a competent adult of the right to forego or discontinue life-saving treatment.”

1.42 These views, expressed by a leading Irish judge, even if written outside his judicial role, strongly support the concept that an advance care directive would be enforceable in Irish law. Indeed, they were also expressly referred to ten years later in a very similar Irish case.

(b) The Ward of Court case (1996)

⁴⁷ Irish Council for Bioethics *Is It Time for Advanced Healthcare Directives?* (2007).

⁴⁸ Costello “The Terminally Ill-The Law’s Concern” (1986) 21 *Irish Jurist* 35.

⁴⁹ 355 A 2d 647 (1976): see paragraph 1.15, above.

⁵⁰ Costello “The Terminally Ill – The Law’s Concerns” (1986) 21 *Irish Jurist* 35, at 42.

1.43 Ten years after Costello J delivered his lecture, his comments were cited with approval in the Irish equivalent of the *Quinlan* case, *Re a Ward of Court (No 2)*.⁵¹ This case involved a 46 year old woman,⁵² who had suffered severe brain damage during a routine surgical procedure 24 years previously. During those 24 years, she had been in a near persistent vegetative state (near PVS). Initially, she had been fed through a nasogastric (ng) tube, but this was later replaced by the second major form of artificial feeding tube, the percutaneous endoscopic gastrostomy tube, usually called a PEG tube. Her mother applied for directions from the courts as to the proper care and treatment of her daughter. As with the other cases already discussed, such as *Quinlan*, *Cruzan* and *Bland*, the issue for the courts was whether it was permissible in Irish law to withdraw the medical treatment, in particular the form of artificial and nutrition and hydration (ANH) being given to her through the PEG tube feeding.

1.44 The High Court (Lynch J) and, on appeal, the Supreme Court (Hamilton CJ, O’Flaherty, Blayney and Denham JJ; Egan J dissenting) broadly followed the approach taken by the House of Lords in the *Bland* case and held that it was in the woman’s best interests that the artificial nutrition and hydration (ANH) should be withdrawn and that she should be allowed “to die in accordance with nature with all such palliative care and medication as is necessary to ensure a peaceful and pain-free death.” The High Court and, on appeal, the Supreme Court, stated that this withdrawal was lawful. The courts also declared that, after this, the non-use of antibiotics for treatment of infections, other than in a palliative way to avoid pain and suffering, was also lawful. The courts also made an order allowing the woman’s family to make such arrangements as they considered suitable to admit her to a facility that would not regard the withdrawal of ANH to be contrary to their code of ethics.⁵³

⁵¹ [1996] 2 IR 79.

⁵² The case was heard *in camera* and the parties were not identified at the time of the court proceedings: see *Re a Ward of Court (No 1)* [1996] 2 IR 73. Ten years later, in 2006, her mother Margaret Chamberlain wrote to *The Irish Times* (11 April 2006) identifying herself and naming her daughter Lucy Chamberlain as the “Ward of Court” in the title of the 1996 case. Her letter had been prompted by another high-profile end-of-life case in the United States, the Terri Schiavo case: see paragraph 1.20, above.

⁵³ The broad form of the orders made are set out at [1996] 2 IR 79, at 99.

1.45 In the Supreme Court, Hamilton CJ specifically quoted from and approved the views expressed by Costello J in his 1986 lecture on the terminally ill.⁵⁴ He added:⁵⁵

“A competent adult if terminally ill has the right to forego or discontinue life-saving treatment... and that the exercise of that right would be lawful and in pursuance of [the person’s] constitutional rights.”

1.46 Similarly, O’Flaherty J stated:

“consent to medical treatment is required in the case of a competent person... and, as a corollary, there is an absolute right in a competent person to refuse medical treatment even if it leads to death.”⁵⁶

He considered that “it would be correct to describe the right in our law as founded both on the common law as well as the constitutional rights to bodily integrity and privacy.”⁵⁷ Denham J agreed, adding that:

“...medical treatment may be refused for other than medical reasons, or reasons most citizens would regard as rational, but the person of full age and capacity may make the decision for their own reasons.”⁵⁸

1.47 Although the *Ward of Court* case did not require the courts to deal directly with advance care directives, as in *Bland* the Supreme Court made indirect references to the issue. O’Flaherty J stated that he found it:

“impossible to adapt the idea of the ‘substituted judgment’ to the circumstances of this case and, it may be, that it is only appropriate *where the person has had the foresight to provide for future*

⁵⁴ [1996] 2 IR 79, at 125.

⁵⁵ *Ibid*, at 125-6.

⁵⁶ *Ibid* at, 129.

⁵⁷ *Ibid*.

⁵⁸ *Ibid* at 156. It is interesting to note that the following italicised line in the unreported approved judgment of Denham J in *Re a Ward of Court (No 2)* 27 July 1994 at 24 does not appear in either *In re a Ward of Court (withholding medical treatment) (No 2)* [1996] 2 IR 79 at 156 or *In re a Ward of Court (withholding medical treatment) (No 2)* [1995] 2 ILRM 401 at 454:

“...medical treatment may be refused for other than medical reasons. *Such reasons may not be viewed as good medical reasons*, or reasons most citizens would regard as rational, but the person of full age and capacity may take the decision for their own reasons.”

eventualities. That must be unusual (if it ever happens) at the present time; with increased publicity in regard to these type of cases it may get more common.”⁵⁹

1.48 Campbell has argued that O’Flaherty J’s comments suggest that if an individual had the foresight to express his wishes in an advance directive, an Irish court would uphold its validity.⁶⁰ Furthermore, Madden suggests that a court would uphold the validity of an advance directive provided first, that the author was competent and informed when drafting it, and second, that it was clear and specific to the patient’s current situation. She contends that this is in keeping with the court’s development of the unenumerated constitutional right to refuse medical treatment.⁶¹ Mills, having described *Ward* as a “categorical exaltation of personal autonomy”, notes that its only logical corollary is that an “advance statement, properly made and containing no directives that were themselves unlawful, would be acceptable to Irish law.”⁶²

(c) K Case on Blood Transfusions (2006 and 2008)

1.49 In *Fitzpatrick v FK*,⁶³ the High Court made an interlocutory order that a 23-year old Congolese woman (Ms K) who had refused a blood transfusion should be given the transfusion against her will in order to save her life. Despite finding that Ms K was competent to make healthcare decisions, Abbott J found that the welfare of Ms K’s new born child, with no other apparent parent, was paramount and should override the wishes of his mother. The High Court had previously ordered transfusions to be administered in cases where there was doubt as to the capacity of the patient to refuse, or where the decision to refuse treatment was made by a parent on behalf of a child. On the basis of the evidence, however, Ms K was neither incapacitated nor a minor.

1.50 It is thus unsurprising that a full hearing of the issues in the case later came before the High Court (Laffoy J) in *Fitzpatrick v FK (No 2)*⁶⁴ to determine whether the transfusion given on the basis of the interlocutory order had been lawfully given. Having undertaken a review of case law on mental capacity from other jurisdictions, Laffoy J held that the following six principles were applicable

⁵⁹ [1996] 2 IR 79, at 133 (*italics added*).

⁶⁰ Campbell “The Case for Living Wills in Ireland” (2006) 12(1) *Medico-Legal Journal of Ireland* 2, at 6.

⁶¹ Madden *Medicine, Ethics & the Law* (Tottel Publishing 2002), at paragraph 11.57.

⁶² Mills *Clinical Practice and the Law* (2nd ed Tottel Publishing 2007), at paragraph 329.

⁶³ [2006] IEHC 392, [2008] 1 ILRM 68.

⁶⁴ [2008] IEHC 104.

when determining the capacity question. The first principle states that there is a rebuttable presumption that an adult patient has the capacity to make a decision to refuse medical treatment. The Commission notes that this is consistent with the Commission's recommendation in its 2006 *Report on Vulnerable Adults and the Law*⁶⁵ that mental capacity legislation contain a rebuttable presumption of capacity,⁶⁶ and this is included in the Government's *Scheme of a Mental Capacity Bill 2008* which was published in September 2008.⁶⁷

1.51 Second, in determining whether a patient is deprived of capacity to make a decision to refuse medical treatment, Laffoy J stated that the test is:

“whether the patient's cognitive ability has been impaired to the extent that he or she does not sufficiently understand the nature, purpose and effect of the proffered treatment and the consequences of accepting or rejecting it in the context of the choices available (including any alternative treatment) at the time the decision is made.”⁶⁸

1.52 The Commission notes that this decision-specific cognitive test of mental capacity is also consistent with the Commission's recommendation in its 2006 *Report on Vulnerable Adults and the Law* and this is also included in the Government's *Scheme of a Mental Capacity Bill 2008*.

1.53 The third principle set out by Laffoy J was that the three-stage approach to the patient's decision-making process adopted in the English case *Re C*,⁶⁹ which involved the refusal of an amputation,⁷⁰ is a “helpful tool” in applying that test. Laffoy J specifically noted that the Commission's proposed statutory functional test of capacity (in the 2006 *Report on Vulnerable Adults and the Law*⁷¹) was consistent with the test in *Re C*. In applying *Re C* to the facts of the case Laffoy J held, first, that Ms K did not sufficiently understand and retain the information given to her by the Hospital personnel as to the necessity of a blood transfusion to preserve her life; second, that she did not believe that information and, in particular, that she did not believe that she was likely to die without a blood transfusion being administered; and finally, that in

⁶⁵ LRC 83-2006.

⁶⁶ See paragraph 1.08, above.

⁶⁷ Available at www.justice.ie

⁶⁸ Citing Lord Donaldson in *Re T (refusal of medical treatment)* [1992] 4 All ER 649.

⁶⁹ *Re C (adult: refusal of treatment)* [1994] 1 WLR 290.

⁷⁰ See the discussion in paragraph 1.28, above.

⁷¹ See paragraph 1.08, above.

making her decision to refuse a blood transfusion, Ms K had not properly weighed that information in the balance, balancing the risk of death inherent in that decision and its consequences, including its consequences for her newborn baby, against the availability of a blood transfusion that would preserve her life.

1.54 The fourth principle set out by Laffoy J was that, with regard to the treatment information by reference to which the patient's capacity is to be assessed, a clinician is under a duty to impart information as to what is the appropriate treatment, that is:

“what treatment is medically indicated, at the time of the decision and the risks and consequences likely to flow from the choices available to the patient in making the decision.”

Laffoy J held that Ms K's clinicians had given her the information necessary to enable her to make an informed decision as to whether to accept or refuse a blood transfusion. That information was conveyed in layman's terms from which a competent adult whose capacity was not impaired should have understood the gravity of the situation. The fifth principle set out by Laffoy J was that a distinction was to be drawn between a misunderstanding of the treatment information in the decision-making process, which may be evidence of lack of capacity, and an irrational decision, which is irrelevant to the assessment.

1.55 The sixth principle discussed by Laffoy J was that the assessment of capacity must have regard to “the gravity of the decision, in terms of the consequences which are likely to ensue from the acceptance or rejection of the proffered treatment.” Laffoy J rejected the suggestion of Ms K's counsel that the patient's capacity should be measured against the nature of the decision, rather than its consequences, citing the decision of the Supreme Court in *Re a Ward of Court (No 2)*⁷² in support. When refusing a blood transfusion, Ms K had suggested to the Master of the Hospital that Coca-Cola and tomatoes might be an alternative solution to a blood transfusion. Laffoy J held that this suggestion could “only ring alarm bells” as to Ms K's appreciation of the gravity of the situation when viewed objectively.

1.56 Laffoy J concluded that Ms K's capacity was impaired to the extent that she did not have the ability to make a valid refusal to accept a blood transfusion. Therefore, the administration of the transfusion was not an unlawful act, and did not constitute a breach of her rights either under the Constitution or the Convention.

⁷² [1996] 2 IR 79.

(d) Current use of advance care directives in Ireland and calls for a legislative framework

1.57 As O’Flaherty J noted in the *Ward of Court* case the corollary to the right to consent is the right to refuse medical treatment. Although there is currently no legislative framework for advance care planning in Ireland, many people have prepared written advance care directives, sometimes with the benefit of medical and legal advice, and general hospitals deal on a regular basis with patients who verbally express treatment preferences, including refusals of treatment and “do not resuscitate” requests.⁷³ In a study conducted in 2003, 27% of physicians had experience of advance care directives made by Irish patients.⁷⁴ The Commission is also aware that a number of hospitals in Ireland have developed guidelines and protocols to deal with advance care directives, based on best practice models from other States, notably the UK.⁷⁵

1.58 In 2007, the Irish Council for Bioethics, having engaged in extensive public consultation and having conducted an opinion poll which supported the introduction of a legal framework in this area, published its Opinion *Is It Time for Advance Healthcare Directives?*⁷⁶ In this Opinion, the Council stated that the “lack of legislation makes the status of advance directives unclear” and that, in turn, the lack of clarity was a result of the limited number of cases that had discussed the issues of a patient’s previous wishes regarding treatment.⁷⁷ The Council therefore concluded that “there is both a need and an opportunity to develop a legal framework for advance directives to facilitate their use and implementation.”⁷⁸ The Commission also notes that the Council’s Opinion contains some sample advance care directives, drawn from a number of different States.⁷⁹

⁷³ Irish Council for Bioethics, Opinion, *Is It Time for Advance Healthcare Directives?* (2007), pp.6-9.

⁷⁴ Fennell, Butler, Saaidin and Sheikh, “Dissatisfaction with Do Not Attempt Resuscitation Orders: A Nationwide Study of Irish Consultant Physician Practices” (2006) 99(7) *Irish Medical Journal* 208.

⁷⁵ Information supplied to the Commission during the consultation process.

⁷⁶ Available at www.bioethics.ie

⁷⁷ Irish Council for Bioethics, Opinion, *Is It Time for Advance Healthcare Directives?* (2007), at 6.

⁷⁸ *Ibid* at 15.

⁷⁹ *Ibid*, pp.70-84 (Appendix 4).

(6) Conclusions on the need for a legislative framework

1.59 The Commission has already noted that the State's international obligations, in particular under the 2006 UN *Convention on the Rights of Persons with Disabilities* and the Council of Europe's 2009 *Draft Recommendation on Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity*,⁸⁰ reinforce the arguments in favour of legislation in this area.

1.60 It is also clear that legislation on advance care directives should be placed in the wider setting of the general law on mental capacity. In its 2006 *Report on Vulnerable Adults and the Law*⁸¹ the Commission indicated that it would deal with advance care directives separately from its general proposals for reform made in that Report. Nonetheless, the Commission also included in the Report and its *Draft Scheme of a Mental Capacity Bill* a general principle that "account must be taken of the person's past and present wishes where they are ascertainable."⁸² This is consistent with Article 9 of the Council of Europe 1997 *Convention on Human Rights and Biomedicine* and the 2009 *Draft Recommendation on Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity*.⁸³ The Commission very much welcomes that Head 1 of the Government's *Scheme of a Mental Capacity Bill 2008*, which proposes to implement the Commission's 2006 Report, also contains this legislative guiding principle.

1.61 On the basis of the review of relevant case law and developments at international level, including the Council of Europe's 2009 *Draft Recommendation on Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity*,⁸⁴ the Commission has concluded that there is a growing momentum favouring the introduction of a legislative framework for advance care directives. To the extent that case law in Ireland, notably *In re a Ward of Court (No.2)*⁸⁵ and *Fitzpatrick v FK*,⁸⁶ has addressed this matter, it is clear that an advance care directive made by a person with full capacity would

⁸⁰ See paragraphs 1.30-1.36, above.

⁸¹ LRC 83-2006.

⁸² LRC 83-2006, at paragraph 2.106; and Head 4 of the *Draft Scheme of a Mental Capacity Bill* (Report Appendix, p.171).

⁸³ See paragraphs 1.32-1.36, above.

⁸⁴ See paragraphs 1.32-1.36, above.

⁸⁵ [1996] 2 IR 79.

⁸⁶ *Fitzpatrick v FK* [2006] IEHC 392, [2008] 1 ILRM 68 and *Fitzpatrick v FK (No 2)* [2008] IEHC 104.

be upheld. Indeed, this conclusion follows from the experience in other States, including the United States and the UK.

1.62 In the absence of a clear legislative framework, the Commission acknowledges that health care professionals have faced difficulties in dealing with the many complex issues arising from advance decision making. The Commission has concluded that, due to the complexity of many of the issues involved, a clear statutory framework is necessary. In light of the general setting of the law on capacity in which advance care directives are considered, it is appropriate that this legislative framework should be placed within the wider framework of the reform of the law on mental capacity. The Commission therefore recommends that an appropriate legislative framework should be enacted for advance care directives, as part of the wider context of reform of the law on mental capacity in the Government's *Scheme of a Mental Capacity Bill 2008*.

1.63 *The Commission recommends that an appropriate legislative framework should be enacted for advance care directives, as part of the reform of the law on mental capacity in the Government's Scheme of a Mental Capacity Bill 2008.*

(7) The legislative framework in a wider health care setting

1.64 In the Commission's view, any legislative framework must be seen in the context of the ongoing development of good medical practice. In that respect, the Commission considers it important not to see an advance care directive merely as an end in itself – a legal “event” so to speak – but also as part of a wider process that could facilitate the development and improvement of healthcare planning.

1.65 Central to healthcare planning is good communication between patients and medical professionals. Good communication results in improved informed decision making, which is consistent with the concept of informed consent and greater patient autonomy. This should also form part of any proposed legislative scheme for advance care directives.⁸⁷ In developing the concept of a health care plan, the patient is encouraged to make decisions about their overall care plan. In order for this to reflect reality advice can and should be sought from doctors, nurses, midwives or other health care professionals.⁸⁸ Treatment should be explained to patients in a way they can understand and they should be encouraged to ask questions. Through this process, the patient can then make an informed and truly autonomous decision.

⁸⁷ See paragraphs 1.86-1.95, below.

⁸⁸ For more on healthcare professionals see paragraphs 3.02-3.05.

1.66 While many may not wish to discuss difficult health care decisions in advance – including preparations for death and dying - discussions can prevent misunderstanding when the time comes to making medical decisions. These discussions can be with the person’s own local doctor, in a nursing home or in a hospital. While communication is the key to making a healthcare plan, the timing of such a discussion is also critical.⁸⁹ Discussions far in advance of the actual event being discussed, such as stroke or heart attack, may become redundant by the time they actually occur because relevant treatment options may be very different by comparison with the time when the discussion took place. Equally, discussing care options on the day that a person is admitted to a nursing home may not be suitable, as the person is likely to be dealing with other issues such as illness or loss of independence.⁹⁰

1.67 While some of these issues are outside the direct scope of this Report, it is nonetheless worth noting the importance of health care professionals being trained in the process involved in this discussion, and its timing. It is essential that a healthcare plan is tailored to each individual and it based on the wishes of the individual.⁹¹ While this process may be time consuming, it ensures that the preferences of the patient are made known. Thus, a healthcare plan establishes the wishes of a patient and, through this process, the dignity and autonomy of a patient is strengthened.

1.68 In the specific context of end-of-life decision-making, the Irish Hospice Foundation’s Forum on the End-of-Life,⁹² which was launched in March 2009, aims to develop a “vision of how modern Ireland can address the challenges of dying, death and bereavement.”⁹³ The Forum also seeks to determine the key issues at the end of life with input from the views and concerns of the public and various organisations. All types of deaths – sudden, traumatic and expected – form part of the discussions within the Forum. Among the issues raised are the need for a clear policy on the fragmentation of care

⁸⁹ Froggatt, Vaughan, Bernard and Wild *Advance Care Planning in Care Homes for Older People* Final Report (April 2008) at 36.

⁹⁰ O’Shea, Murphy, Larkin, Payne, Froggatt, Casey, Ní Léime and Keys, *End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland* (2008).

⁹¹ A survey conducted by the National Council on Ageing and Older People indicated that the medical profession tend to discuss treatment and services with the family rather than the patient. National Council on Ageing and Older People *Perceptions on Ageism in Health and Social Services in Ireland* (Report No. 85, 2005), at 72.

⁹² www.endoflife.ie

⁹³ *Ibid.*

services, the need for palliative care to be made available in all care settings to persons with dementia and the health and other effects of long term caring on carers. In the specific context of this Report, the Forum is also addressing Do Not Resuscitate Orders.

1.69 The consultations involved in the Forum will conclude at the end of 2009. Regional consultations will begin in 2010 with a final Report scheduled to be published in April 2010. This Report will aim to reflect the views and issues emerging from the forum workshops and submissions. A National Coalition will then be established to advance the work of the Forum. In view of the wide scope of the Forum's deliberations, and its emphasis on planning at end of life, it is clear that advance care directives will form an element of the analysis for the IHF's Report.

1.70 The Commission recognises the importance of the wider healthcare planning framework within which its proposals on advance care directives should be placed. Indeed, this wider setting formed an important part of the discussion at the Commission's Annual Stakeholder Conference in 2008, in which the provisional recommendations in the Consultation Paper were discussed. While the legislative framework envisaged by the Commission may be limited to refusals of treatment (for the reasons identified below),⁹⁴ this does not, for example, preclude the process outlined briefly here of good health care planning between medical professional and their patients. Thus, the proposed legislative framework does not prevent a person from expressing their wishes concerning future medical treatment in the wider context of his or her health care planning. Any legislative framework on advance care directives must, therefore, be facilitative in nature and be seen in the wider setting of overall health care planning and the emergence of the practice of developing individual care plans between a medical professional and his or her patient.

1.71 *The Commission recommends that the proposed statutory framework on advance care directives should be facilitative in nature and be seen in the wider context of a process of health care planning by an individual, whether in a general health care setting or in the context of hospice care.*

D Scope of the Report

1.72 In this Part, the Commission discusses the scope of the recommendations in this Report. The Commission emphasises that the recommendations do not propose to change the effect of any act that is currently prohibited by the criminal law. The Commission then points out that the proposed legislative framework should apply to treatment refusals and that,

⁹⁴ See paragraphs 1.76-1.82, below.

for various practical reasons, it will not encompass advance requests for treatment. The third element concerning the scope of the Report is that the Commission considers that advance care directives concerning mental health treatment (which has been legislated for in other States) deserve separate discussion and consideration, and have been excluded from the Commission's current review of the law.

(1) Advance care directives and the law on euthanasia and assisted suicide

1.73 In the Consultation Paper, the Commission noted that euthanasia is unlawful in Ireland and would, depending on the context, constitute either murder or involuntary manslaughter.⁹⁵ In the Consultation Paper the Commission also noted that there is an extremely important distinction between assisted suicide, which is also unlawful, and an advance care directive that involves a refusal of life-sustaining treatment.⁹⁶ As noted by Lord Goff in the English case *Airedale NHS Trust v Bland*:⁹⁷

“...in cases of this kind, there is no question of the patient having committed suicide, nor therefore of the doctor having aided or abetted him in doing so. It is simply that the patient has, as he is entitled to, declined to consent to treatment which might or would have the effect of prolonging life, and the doctor has, in accordance with his duty, complied with the patient's wishes.”⁹⁸

1.74 In *In re a Ward of Court (No.2)*,⁹⁹ the Supreme Court also emphasised this important distinction, and the Commission fully supports this view. Thus, where a person with capacity refuses treatment that might or would have the effect of prolonging life and the person dies, he or she has not committed suicide and any health care professional who complies with the person's wishes has acted lawfully and has not been involved in any criminal act. The Commission reaffirms in this respect that legislation regarding advance care directives which is consistent with this important distinction would not alter existing law, under which euthanasia and assisted suicide constitute forms of homicide. The Commission therefore emphasises that its final

⁹⁵ *Consultation Paper on Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraph 1.19.

⁹⁶ *Ibid*, at paragraph 1.20.

⁹⁷ [1993] 1 All ER 82.

⁹⁸ *Ibid* at 866.

⁹⁹ [1996] 2 IR 79.

recommendations in this Report do not alter or affect these aspects of current criminal law.

1.75 *The Commission recommends that its proposed legislative framework for advance care directives does not alter or affect current law on homicide, under which euthanasia and assisted suicide are criminal offences.*

(2) *Treatment requests and treatment refusals*

1.76 An advance care directive enables a person to have a degree of autonomy over future healthcare decisions. In the Consultation Paper, the Commission noted an important distinction, namely, that while a person may have a right to decide what is not to be done to their body this does not necessarily mean they have a corresponding right to decide what is to be done to their body.¹⁰⁰ It has been argued that an aspect of the right to autonomy is that a person may demand certain medical treatment, but the Commission notes that a person does not have an absolute right to specific forms of medical treatment, for example a demand that the State pay for a transplant operation. In that respect, because this would involve very wide issues of clinical judgement and the appropriate use of limited State resources the Commission considers that its proposed legislative framework could not apply to such situations.

1.77 The Commission notes that while there is no general legally enforceable right to demand specific medical treatment, a person is perfectly entitled to express their preferences. A person may, for example, wish to try an alternative course of treatment. While the medical professional may not consider the treatment to be particularly worthwhile, they might still agree to pursue it. Thus, in practice an advance care directive, seen in the wider context of health care plans and planning, could include requests about where a person would like to be treated or where they would like to live in later years. For the reasons already mentioned, this aspect of a directive would not have the legal status envisaged in the Commission's legislative scheme. The Commission is aware that, while the majority of Irish people wish to die at home, only 20% do so.¹⁰¹ This is not to say that an advance care directive, or for that matter a health care plan, can change that reality, but it may assist in focusing an individual's need to plan how to change the wish into reality more often.

¹⁰⁰ Law Reform Commission *Consultation Paper Bioethics Advance Care Directives* (LRC CP 51-2008), at paragraph 1.23.

¹⁰¹ O'Shea, Keegan, McGee "End-of-Life Care in General Hospitals: Developing a Quality Approach for the Irish Setting" Health Services Research Centre, Department of Psychology, Royal College of Surgeons in Ireland (2002), at 29.

1.78 A related question arises as to whether a person could request in advance that their medical treatment should continue indefinitely to sustain their life. In general terms, the Commission agrees that a health care professional should not be forced to provide treatment which would be in conflict with their medical judgement.¹⁰² In this respect, the Irish Medical Council provides the following ethical guidance to its members:¹⁰³

“Where death is imminent, it is the responsibility of the doctor to take care that the sick person dies with dignity, in comfort, and with as little suffering as possible. In these circumstances a doctor is not obliged to initiate or maintain treatment which is futile or disproportionately burdensome.”

The Commission considers that this guidance deals correctly with a difficult ethical matter in a manner that is also consistent with existing criminal law on euthanasia, already discussed.

1.79 Concern was expressed to the Commission during the consultation process that if a proposed legislative framework for advance care directive extended only to refusals of medical treatment this may result in the person not receiving other treatment which they had not specifically refused, particularly if the person concerned is an older person. The Commission is strongly of the view that an advance care directive should not be interpreted as involving a refusal of other forms of medical treatment which are not mentioned in the advance care directive. Medical treatment should be given to a person unless that treatment is refused in an advance care directive or if a health professional considers the treatment to be contrary to good medical practice. Subject to this caveat, the Commission has concluded that it would not be practical or appropriate from an ethical perspective to include in the proposed legislative framework advance care directives which involve a request for treatment.

1.80 Submissions received by the Commission supported a legislative scheme concerning advance care directives that involve refusals of treatment, but it was noted that it would not be appropriate to provide that an advance care directive could refuse all types of treatment, such as basic care. The Commission is in agreement with this basic premise.

1.81 The Commission has, therefore, concluded that the proposed legislative framework should apply to an advance care directive that involves a

¹⁰² Irish Medical Council *A Guide to Ethical Conduct and Behaviour* (6th ed 2004) at paragraph 23.1. BMA “Advance Decisions and Proxy Decision-Making in Medical Treatment and Research” (2007), at 5.

¹⁰³ Irish Medical Council *A Guide to Ethical Conduct and Behaviour* (6th ed 2004), at paragraph 23.1.

refusal of medical treatment, subject to certain conditions. The Commission discusses the parameters of these conditions in Chapter 3 of this Report. The Commission recommends that the proposed legislative scheme should draw on section 24(1) of the English *Mental Capacity Act 2005*, which defines an “advance decision” as meaning a decision made by a person of 18 years with capacity to do so that if “(a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and (b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued.” The Commission also recommends that the definition in the proposed legislative scheme should also take account of the definition in advance directive proposed in the Council of Europe 2009 *Draft Recommendation on Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity*,¹⁰⁴ namely, the expression of instructions or wishes made by an adult person with capacity concerning medical care that may arise in the event of his or her incapacity.

1.82 *The Commission recommends that the proposed legislative framework should apply to advance care directives that involve refusal of treatment, subject to certain conditions to be specified in the legislation. The Commission also recommends that an advance care directive should be defined as the expression of instructions or wishes by a person of 18 years with capacity to do so that, if (a) at a later time and in such circumstances as he or she may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him or her, and (b) at that time he or she lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued.*

(3) Advance care directives and mental health care

1.83 In the Consultation Paper the Commission pointed out that the scope of the current project did not extend to advance care directives involving mental health care. The Commission accepts, of course, that an advance care directive made in the context of a recurring illness history and the use of effective medication during previous psychiatric episodes could improve the person’s adherence to a treatment plan, with its consequent benefits in terms of quality of life and reduced need for hospitalisation.¹⁰⁵ Nonetheless, the Commission has concluded that this aspect of advance care directives involves many issues in addition to those discussed in this Report, and is, therefore, deserving of separate analysis. This would include the impact of the specific legislative

¹⁰⁴ See paragraphs 1.33-1.38, above.

¹⁰⁵ Exworthy “Psychiatric Advance Care Decisions – An Opportunity Missed” (2004) *Journal of Mental Health Law* 129.

framework contained in the *Mental Health Act 2001*, and the developing work of the Mental Health Commission in this area. For these reasons, the Commission has concluded that the proposed legislative framework should not apply to advance care directives involving mental health care, but that this should be subject to review and separate analysis at a future date.

1.84 *The Commission recommends that the proposed legislative framework should not apply to advance care directives involving mental health care.*

E Underlying Rights and Principles

1.85 In this Part, the Commission sets out the general rights and principles it considers should inform the legislative framework for advance care directives. These are derived primarily from the discussion of the case law and relevant international instruments that have been discussed in Part C, above. The relevant rights and principles are: the right to consent to, and to refuse, medical treatment; the principle of autonomy in the wider legal and ethical setting; the rights to privacy and dignity; and a presumption in favour of preserving life in the interpretation of advance care directives.

(1) *The right to consent to, and to refuse, medical treatment*

1.86 It is a well established general principle that a person must consent to medical treatment. As with many general principles, there are a number of exceptions to this, such as in a medical emergency where the patient is unable to communicate and in the case of contagious diseases. As Costello J noted in his 1986 lecture on the terminally ill, the corollary to the right to consent is the right to refuse medical treatment.¹⁰⁶ Indeed, the general right to refuse medical treatment was affirmed in Irish law by the Supreme Court decision in *In re a Ward of Court (No 2)*.¹⁰⁷ In the context of advance care directives, the Commission discusses here the relevance of informed decision making, the position concerning demands for medical treatment and expressing wishes concerning treatment.

1.87 There is a rebuttable presumption in law that a person has the capacity to consent to and to refuse medical treatment.¹⁰⁸ Before a person

¹⁰⁶ See Costello, “The Terminally Ill –the Law’s Concerns” (1986) 21 Ir Jur 35 at 42. See the discussion of the lecture at paragraph 1.41, above.

¹⁰⁷ [1996] 2 IR 79. See paragraphs 1.43-1.48, above.

¹⁰⁸ A presumption of capacity exists at common law, and the Commission has recommended that this be placed on a statutory footing: see *Report on Vulnerable Adults and the Law* (LRC 83-2006), paragraphs 2.34 – 2.39, and section 6 of the draft *Scheme of the Mental Capacity and Guardianship Bill*

consents to or refuses medical treatment, he or she must be given all the necessary medical information about the procedure or the implications of refusing the treatment. Crucially, the patient must understand the implications of such a procedure. As Maclean has stated “autonomy requires knowledge and not information.”¹⁰⁹

1.88 Traditionally, medical professionals, in particular doctors, have been the information givers. In recent years, the prevalence of medical information, whether in book form or on the internet, has resulted in people learning about treatment options from non-traditional methods. An informed decision can often be made by reading such materials. What is important is that a person understands what they are refusing and what implications will arise. As already mentioned, in the *Ward of Court* case, a person has the right to make a decision that is contrary to medical advice, or to make a decision that may appear irrational.

1.89 It has been argued that, if the right to refuse medical treatment is driven by principles of self-determination and autonomy, “the individual should be allowed to chose how well informed the decision is.”¹¹⁰ An informed decision ensures that the person understands the implications of their decision.¹¹¹ Medical professionals must not, however, confuse an irrational decision with a patient who does not understand the implications of refusing treatment.

1.90 In this respect, concern has been expressed that “patients will be labelled as incompetent simply because they have not chosen the option that some other person (particularly their doctor) would have chosen.”¹¹² On this point, the Commission supports the view expressed in the Supreme Court

appended to that Report. Head 1(a) of the *Scheme of the Mental Capacity Bill 2008*, published by the Department of Justice, Equality and Law Reform in September 2008 (available at www.justice.ie), and which is based on the Commission’s 2006 Scheme, proposes the following: “it shall be presumed unless the contrary is established that a person has capacity.”

¹⁰⁹ Mclean “Autonomy, Consent and Persuasion” (2006) 13 *European Journal of Health Law* 321, at 326.

¹¹⁰ Maclean “Advance Directives and the Rocky Waters of Anticipatory Decision-Making” [2008] 16 *Medical Law Review* 1, at 14.

¹¹¹ Mclean has argued that this relatively minor infringement on autonomy is justified as it gives enhanced security to what can often be “a fundamental life choice”. *Ibid*, at 15.

¹¹² Morris “Life and Death Situations: “Die my Dear Doctor? That’s the Last Thing I Shall Do”” (1996) 3 *European Journal of Health Law* 9, at 20.

decision in *In re a Ward of Court (No 2)*¹¹³ that a person with full mental capacity is entitled to refuse medical treatment even if this leads to his or her death.¹¹⁴ As the Supreme Court has also noted, a person may also refuse treatment for religious reasons.¹¹⁵ While the State has a general interest in preserving life on behalf of society, the right to refuse medical treatment does not disappear in situations where medical treatment can sustain life.¹¹⁶ In this respect, the law recognises that a person is entitled to refuse medical treatment even where this is in conflict with the best available medical advice and is not based on any objectively rational reasons.

1.91 In other words, a person of full age and capacity is entitled to refuse medical treatment for their own reasons, even if other people would think that those reasons were not rational or not based on sound medical principles. This is consistent with the Commission's view in its 2006 *Report on Vulnerable Adults and the Law*, and which is incorporated into the Government's *Scheme of a Mental Capacity Bill 2008*, that capacity be defined by reference to a functional approach, in which cognitive understanding of the decision to be made, rather than outcome, is the key factor. The Commission accordingly recommends that informed decision making should be a principle that forms part of the legislative framework on advance care directives. The Commission also recommends that it should be made clear that a person is entitled to refuse medical treatment for reasons that appear not to be rational or based on sound medical principles or for religious reasons.

1.92 *The Commission recommends that informed decision making should be a principle that forms part of the legislative framework on advance care directives. The Commission also recommends that it should be made clear that a person is entitled to refuse medical treatment for reasons that appear not to be rational or based on sound medical principles and to refuse medical treatment for religious reasons.*

1.93 The Commission returns in Chapter 3 to discuss in detail the application of these principles.¹¹⁷

¹¹³ [1996] 2 IR 79.

¹¹⁴ [1996] 2 IR 79, at 129. See Law Reform Commission *Consultation Paper on Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraph 2.03.

¹¹⁵ *In re a Ward of Court (No 2)* [1996] 2 IR 79, at 160.

¹¹⁶ *Ibid*, at 163.

¹¹⁷ See paragraph 3.66 to 3.70, below.

(2) *Autonomy, dignity and privacy*

(a) *Autonomy*

1.94 The concept of autonomy recognises that a person has a general right to decide how to live their life. In the context of medical treatment, the concept of autonomy is consistent with the gradual move from a paternalistic model in which “doctor knows best” to a more patient-centred approach.¹¹⁸ A patient’s right to decide on their medical treatment thus gives a patient more control over their own life. In the English case *Re T*¹¹⁹ Lord Donaldson MR noted that:

“The patient’s interest consists of his right to self-determination - his right to live his own life as he wishes even if it would damage his health or lead to his premature death.”¹²⁰

1.95 It has been argued that the emergence of the concept of autonomy has eroded the principle of the sanctity of life.¹²¹ While the State has an interest in preserving life, this interest must be balanced against the right of a person to decide how they live their life. Indeed, the Commission agrees with the view that the sanctity of life is not necessarily consistent with keeping a person alive at all costs. Treatment which is excessively burdensome, which is of no medical benefit, or treatment which is against the clearly stated wishes of the patient, but which does keep a patient alive, is not consistent with the principle of the sanctity of life. As Hamilton CJ noted *In re a Ward of Court (No 2)*¹²², the right to life “includes the right to have nature take its course and to die a natural death.” A person can choose to decline treatment which has “no curative effect and which is intended merely to prolong life.”¹²³

(b) *Rights to privacy and dignity*

1.96 The rights to privacy and dignity have been accepted as constitutional rights under Article 40.3 of the Constitution of Ireland. The courts

¹¹⁸ Bagheri “Regulating Medical Futility: Neither Excessive Patient’s Autonomy Nor Physician’s Paternalism” (2008) 15 *European Journal of Medical Ethics* 45 at 48.

¹¹⁹ [1992] 4 All ER 649.

¹²⁰ *Ibid* at 661.

¹²¹ Keown “The Legal Revolution: From “Sanctity of Life” to “Quality of Life” and “Autonomy”” (1998) 14 *Journal of Contemporary Health Law and Policy* 253, at 253.

¹²² [1996] 2 IR 79.

¹²³ *Ibid*, at 124.

have recognised that both rights are interlinked as the “nature of the right to privacy must be seen as to ensure the dignity and freedom of an individual.”¹²⁴

1.97 In *In re a Ward of Court (No 2)*¹²⁵ Denham J noted that the 44 year old woman in that case, who had been in a persistent vegetative state (PVS) for over 20 years, had a constitutional right to be treated with dignity and that this right does not disappear when a person becomes incapacitated. The Supreme Court in that case decided that the insertion of a tube to feed the woman was intrusive and constituted an interference with the integrity of her body.¹²⁶ Denham J also noted that “merely because medical treatment becomes necessary to sustain life does not mean that the right to privacy is lost.”¹²⁷ The right to privacy and dignity remains while a person is alive and is not dependent on capacity.

1.98 The Commission agrees with the views expressed in the *Ward of Court* case that respect for a person’s treatment preferences is consistent with their right to privacy and, in the context of decisions at the end of life, is consistent with the right to a dignified death. This should be reflected in the Commission’s proposed statutory framework for advance care directives.

1.99 In its 2006 *Report on Vulnerable Adults and the Law* the Commission recommended that the proposed mental capacity legislation should include a guiding principle that due regard be given to a person’s dignity, privacy and autonomy,¹²⁸ and the Commission very much welcomes that this has been incorporated into the Government’s *Scheme of a Mental Capacity Bill 2008*. The Commission is equally of the opinion that the principles of autonomy, dignity and privacy of the individual should form part of the legislative framework for advance care directives, in the wider context of the Government’s proposed mental capacity legislation.

1.100 *The Commission recommends that the principles of autonomy, dignity and privacy of the individual should form part of the legislative framework for advance care directives.*

¹²⁴ *Kennedy v Ireland* [1987] IR 587, at 592 (Hamilton P).

¹²⁵ [1996] 2 IR 79, at 163.

¹²⁶ [1996] 2 IR 79, at 124-125 per Hamilton CJ.

¹²⁷ *Ibid*, at 163.

¹²⁸ *Report on Vulnerable Adults and the Law* (LRC 83-2006), paragraph 2.106; and section 4(e) of the *draft Scheme of a Mental Capacity Bill* (Appendix to Report, p.171).

(3) Presumption in favour of preserving life in the interpretation of advance care directives

1.101 Advance care directives ensure that a person may retain control and autonomy over future treatment decisions but, as already noted, the right to autonomy is not absolute. The Commission turns now to discuss whether, if a doubt exists about the validity or meaning of an advance care directive, this doubt should be resolved in favour of preserving life. This is, of course, relevant only in the context of end of life settings.

1.102 In the English case *Re T*,¹²⁹ Lord Donaldson MR suggested that, where there was such a doubt, this should be resolved by a presumption in favour of life.¹³⁰ The Commission sees general merit in this approach but also accepts that it is not free of difficulties. There is the understandable fear that this approach could be widely used simply to ignore an advance care directive.¹³¹ It has been argued that an alternative way to deal with doubts about the validity or meaning of an advance care directive is to begin without any presumption one way or the other but to take into account the fact that the patient has made an advance care directive. This would take into account that the patient has engaged with the thought of dying and if he or she wants to die and is an indication that the patient felt strongly about having his or her wishes and values respected at the end of life, and that the patient does not in every situation regard life as preferable to death. The law should then uphold these wishes if at all possible.¹³²

1.103 The Commission accepts that this might address the potential problem of using a presumption to ignore an advance care directive, but the reality is that it does not address the key questions of: what type of doubt is to be taken into account (and whose doubt) and should the imminence of the end of life be given some weight?

1.104 The Commission considers that any presumption should not be used to render inoperative the clear decision of an autonomous person. A bias in

¹²⁹ [1992] 4 All ER 649.

¹³⁰ [1992] 4 All ER 649, at 661 (Lord Donaldson MR).

¹³¹ Michalowski "Advance Refusals of Life-Sustaining Medical Treatment: The Refusal of an Absolute Right" (2005) 68 (6) *Modern Law Review* 958, at 962.

¹³² Michalowski "Advance Refusals of Life-Sustaining Medical Treatment: The Refusal of an Absolute Right" (2005) 68 (6) *Modern Law Review* 958, at 962.

favour of life should not in itself generate doubts¹³³ as the making of an advance care directive is indicative that the maker had strong feelings on the issue.¹³⁴ If a medical professional has doubts as to the validity or meaning of an advance care directive, he or she must consult with any relevant proxy or proxies¹³⁵ to discuss whether such a doubt is applicable. In the absence of an appointed proxy or proxies, the medical professional should discuss the matter with the patient's family and friends. The Commission also considers that a medical professional should, in such a case, seek a second opinion from a colleague. Equally, if the family has doubt as to the validity of the advance care directive, the family must consult with any proxy or proxies and the medical professional.

1.105 If this process is followed, the Commission considers that many potential situations of conflict will be resolved, as indeed they are at present. The Commission considers that, if doubt remains after this process, it would *then* be appropriate to reflect in the legal framework the implications of refusing medical treatment where life might be brought to an end. This will be especially so if an advance care directive appears to involve refusal of life-sustaining medical treatment. In this respect, assuming the consultative process outlined has been followed, the Commission has concluded that a presumption in favour of preserving life would be justified as being consistent with the high value placed on the constitutional right to life in the hierarchy of rights.¹³⁶ The Commission therefore recommends that if, following an appropriate process of consultation, a reasonable doubt exists as to the validity or meaning of an advance care directive, any such doubt must be resolved in favour of preserving life.

1.106 The Commission recommends that if, following an appropriate process of consultation, a reasonable doubt exists as to the validity or meaning of an advance care directive, any such doubt must be resolved in favour of preserving life.

¹³³ Willmott, White and Howard "Refusing Advance Refusals: Advance Directives and Life-Sustaining Medical Treatment" (2006) 30 *Melbourne University Law Review* 211 at 237.

¹³⁴ Michalowski "Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right" (2005) 68(6) *Medical Law Review* 958, at 962.

¹³⁵ See the discussion of proxies in paragraphs 2.25-CHAPTER 3E(a).

¹³⁶ See *In re a Ward of Court (No 2)* [1996] 2 IR 79 and, more generally, Kelly's *Irish Constitution* (Hogan and Whyte eds) 4th ed (Lexis Nexis, 2006).

CHAPTER 2 ADVANCE CARE DIRECTIVES, HEALTH CARE PROXIES AND OTHER THIRD PARTIES

A Introduction

2.01 In this chapter the Commission discusses how third parties may often be involved in the decision-making process on which a person has expressed his or her wishes in an advance care directive. This arises from the practical reality that, when the time comes to make a specific medical decision, the person who has made the advance care directive is not available to give their views directly. If the advance care directive is a simple “do not resuscitate me in such an event” this may not be a major issue, but quite often it may not be as simple or straightforward as this. Hence the need to nominate another person to make these decisions, often called a health care proxy.

2.02 The Commission discusses the role of a health care proxy in Part D, below. Before doing so, the Commission discusses the role of two other third parties. In Part B, the Commission discusses how a health care proxy appointed by a person with capacity in an advance care directive differs from the arrangements for the appointment of a personal guardian for a person with limited or no capacity envisaged in the Government’s *Scheme of a Mental Capacity Bill 2008*. The Commission also discusses the role of third parties who assist a person with limited or no capacity in an informal way. In Part C, the Commission notes how the proposals in the *Scheme of a Mental Capacity Bill 2008* to extend the role of an attorney appointed under the *Powers of Attorney Act 1996* to include health care decisions would complement, though not supplant the need for, the Commission’s proposals in this Report.

B Personal Guardians and Third Party Informal Decision Making

2.03 The Government’s *Scheme of a Mental Capacity Bill 2008* envisages (in line with the recommendations in the Commission’s 2006 *Report on Vulnerable Adults and the Law*) two different types of third parties of relevance to this Report. The first type is a personal guardian appointed by Court to assist a person with limited or no capacity and the second is a third party who assists a person with limited or no capacity with informal decision making.

(1) The role of personal guardians

2.04 Head 6 of the Government's *Scheme of a Mental Capacity Bill 2008* proposes that the Court of Protection (the High Court) may appoint a Personal Guardian if it has been decided that a person lacks capacity to make decisions concerning his or her personal welfare. The 2008 Scheme envisages that, as far as practicable, the personal guardian is an assisted decision maker, involving the person concerned as much as possible in the decision making process; where the person involved lacks any capacity, the personal guardian would be a substitute decision-maker. Head 7 of the 2008 Scheme envisages that a personal guardian may be directed by the Court to make specific decisions, which may include decisions regarding the personal welfare of a person including the giving and refusing of consent to treatment, but Head 11(5) currently envisages that this would not include life-sustaining medical treatment. The Commission agrees with this restriction as the personal guardian will not have been appointed by the person themselves, but by the Court, and so may be unaware of the wishes of the person.

2.05 The Commission also welcomes the proposed restriction in Head 11(4) of the *Scheme of a Mental Capacity Bill 2008* that a personal guardian may not make a decision which is contrary to a decision made by an attorney appointed under the *Powers of Attorney Act 1996*, to which the Commission returns in Part C, below. In view of the Commission's recommendations on advance care directives in this Report, it would complement the restrictions envisaged in Head 11(4) of the 2008 Scheme if, in any application for the appointment of a personal guardian, any advance care directive made by the person who is the subject of the application be brought to the Court's attention. In this way the Court could give any necessary direction to ensure that a valid and applicable advance care directive is followed by the personal guardian.

2.06 The Commission also considers that if a health care proxy has already been appointed under an advance care directive, the personal guardian should not be granted powers to make personal welfare decisions which would conflict with the powers of the health care proxy; after all, the proxy will have been appointed when the person had capacity and directly expressed a specific wish. This would also be consistent with one of the guiding principles in the Scheme of the 2008 Bill that account must be taken of the past and present wishes of a person. The Commission accordingly recommends that the existence of any advance care directive, including an advance care directive involving the appointment of a health care proxy, be brought to the attention of the Court when it considers the appointment of a personal guardian. The Commission also recommends that the powers of a personal guardian should not include any powers which would conflict with any provision in an advance care directive.

2.07 *The Commission recommends that the existence of any advance care directive, including an advance care directive involving the appointment of a health care proxy, be brought to the attention of the Court when (as envisaged in the Scheme of a Mental Capacity Bill 2008) it considers the appointment of a personal guardian. The Commission also recommends that the powers of a personal guardian should not include any powers which would conflict with any provision in an advance care directive.*

(2) *The role of third parties in informal decision-making*

2.08 As already mentioned, the Government's *Scheme of a Mental Capacity Bill 2008* also envisages a role for a third party who informally assists a person with limited or no capacity with decision making. In its 2006 *Report on Vulnerable Adults and the Law*, the Commission noted that reform of the law on mental capacity (as now envisaged in the Scheme of the 2008 Bill) should accommodate informal decision-making where possible. The Commission noted that, under existing law, where a third party informally assisted a person with limited or no capacity in a day-to-day decision, such as using that person's money to pay for groceries, it might be that the person with limited or no capacity was incapable of agreeing to this, thus potentially leaving the third party open to civil (or criminal) liability. The Commission pointed out that this gap in the law also applied where a third party assisted informally with day-to-day welfare or health care decisions, such as accompanying the person to a routine dental appointment and signing a "consent form." The Commission pointed out that such a consent form had no legal standing, but that reform of the law on mental capacity should, in fact, allow for such consent under what is commonly described as "general authority to act."¹ The Commission therefore recommended that such parties (who are likely to include family members, friends, carers and health care professionals) be protected from liability when they carry out routine acts to enhance the welfare of a person whom they reasonably believe may lack capacity to consent.² The Commission also recommended that where a formal decision-making process exists, for example, an attorney appointed under the *Powers of Attorney Act 1996* (discussed in Part C below), this should take priority over the informal decision-making process.³

2.09 Head 16 of the Government's *Scheme of a Mental Capacity Bill 2008* proposes, as recommended by the Commission, to introduce the concept of a third party being able to engage in informal decision-making (having a general authority to act) in the context of the "personal care, health care or treatment" of

¹ *Report on Vulnerable Adults and the Law* (LRC 83-2006) at paragraph 2.84-2.85.

² *Ibid* at paragraph 2.88.

³ *Ibid* at paragraph 2.86.

a person whose decision-making capacity “is in doubt.” The person making the decisions must take reasonable steps to establish whether the person lacked the capacity to make the particular decision and that the decision is made in the best interests of the person whose capacity is in doubt. Where this is done, the third party does not incur any liability. If expenditure is incurred, Head 16(4) provides that the third party may reimburse himself or herself out of the money in the person’s possession.

2.10 Head 17 of the Scheme of the 2008 Bill provides that a third party may not make a decision which conflicts with a decision made by a personal guardian or an attorney under an enduring power of attorney (EPA). It also provides that the third party informal decision-maker may not refuse artificial life-sustaining medical treatment. The Commission is in agreement with these limitations, which it also recommended in the 2006 Report.⁴ The Commission remains of the view that only someone appointed by a person while they still have capacity may refuse life-sustaining treatment. In the absence of such a person, the Commission considers that only the Court of Care and Protection (the High Court) designated in the Scheme of the 2008 Bill should have the power to make such a decision.

C Enduring Powers of Attorney

2.11 Under an enduring power of attorney (EPA) made in accordance with the *Powers of Attorney Act 1996* a person with capacity (called the donor) may appoint a person (called an attorney or donee) to make certain decisions outlined in the EPA in the event of the donor’s incapacity. The powers conferred in the EPA become effective only after the person loses capacity and the EPA is registered in the High Court in accordance with the provisions of the 1996 Act. It is important, therefore, to note one similarity and three crucial differences between an EPA and an advance care directive. The key similarity is that in both cases a person with capacity sets out in advance his or her wishes about what should be done in the future at a time when he or she no longer has capacity to indicate his or her wishes. The three crucial differences are: (a) an EPA must always be in written form; the EPA must always appoint a third party to carry out his or her wishes; and (c) the EPA is legally effective only after it has been registered in the High Court. These differences underline the formality of an EPA in contrast to the relative informality and facilitative aspect associated with advance care directives.

⁴ *Report on Vulnerable Adults and the Law* (LRC 83-2006), paragraph 2.88 and section 9 of the draft *Scheme of Mental Capacity Bill* at pp.173-4 of the Report.

2.12 The Council of Europe's 2009 *Draft Recommendation on Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity*⁵ notes that, in some member states an EPA is a preferred alternative to the need for formal court decisions appointing third party representatives to act with or on behalf of individuals with limited or no capacity. Such an example is the appointment of a personal guardian envisaged in the Government's *Scheme of a Mental Capacity Bill 2008*. The draft Recommendation also notes that legislation concerning vulnerable adults with incapacity (such as the *Powers of Attorney Act 1996* or the Government's *Scheme of a Mental Capacity Bill 2008*) promotes self-determination and autonomy for vulnerable adults with limited or no capacity. The draft Recommendation recommends that member states introduce or amend legislation on continuing powers of attorney and advance directives to ensure conformity with the principles contained in the draft Recommendation. The Commission concurs with this view and notes that the Government's *Scheme of a Mental Capacity Bill 2008* already conforms substantially to the principles in the draft Recommendation.

(1) Powers under an EPA

2.13 Under the *Powers of Attorney Act 1996*, an attorney has the power to make decisions relating to the property, financial and business affairs of the donor⁶ or decisions regarding the personal care of the donor.⁷ The donor may limit the power of the attorney under the EPA to cover one aspect only or may make a more general power. For example, the power may specify that the attorney has authority to make decisions about property and business affairs only or general authority to make decisions about property, affairs and personal care. The *Scheme of a Mental Capacity Bill 2008*, which will replace the 1996 Act, retains this distinction.

2.14 Under the 1996 Act, an EPA may give the attorney the power "to make any specified personal care decision or decisions on the donor's behalf." A personal care decision is limited to the following decisions:

- where the donor should live;
- with whom the donor should live;
- whom the donor should see and not see;
- what training or rehabilitation the donor should get;
- the donor's diet and dress;

⁵ Available at www.coe.int. See paragraphs 1.35-1.38, above.

⁶ Section 6 of *Powers of Attorney Act 1996*.

⁷ Section 6(6) of *Powers of Attorney Act 1996*.

- inspection of the donor's personal papers;
- housing, social welfare and other benefits for the donor.⁸

2.15 In its 2006 *Report on Vulnerable Adults and the Law*, the Commission recommended that an EPA should be capable of permitting an attorney to make certain healthcare decisions.⁹ Similarly, Principle 3 of the Council of Europe's *Draft Recommendation on Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity*¹⁰ notes that member states should consider enabling an EPA to cover economic and financial matters, as well as health, welfare and other personal matters. In line with this approach, Head 48 of the *Scheme of a Mental Capacity Bill 2008* envisages extending the power of an attorney to personal welfare decisions, which would include a decision on health care which "giving or refusing consent to the carrying out or continuation of treatment by a person providing health care for the donor."¹¹ The Scheme provides, however, that an attorney could not be empowered to refuse to consent to artificial life-sustaining medical treatment, consent to organ donation or consent to non-therapeutic sterilisation; these would be exclusively matters for the High Court.¹²

(2) Life-sustaining treatment

2.16 The Commission notes that the Council of Europe's draft Recommendation states that EPAs are considered to be "a preferred alternative to court decisions on representation." The Commission agrees with this approach, that decisions relating to healthcare should be made outside a court setting where a suitable alternative decision-making process is in place. The Commission notes that as a person must have full capacity when executing an EPA, he or she should have the power to appoint an attorney concerning all aspects of his or her healthcare in the event of his or her incapacity, should they wish to appoint an attorney regarding such decisions.

2.17 The Commission notes the safeguards to protect the donor of the EPA contained in the 1996 Act (and in the Scheme of the 2008 Bill, which will replace the 1996 Act). First a person must have capacity when executing an EPA and the adjudication of capacity is made at the time of execution of the EPA.¹³ Second, a solicitor must interview the donor and be satisfied that the

⁸ Section 4(1) of *Powers of Attorney Act 1996*.

⁹ LRC 83-2006 at 4.32.

¹⁰ Available at www.coe.int. See paragraphs 1.35-1.38, above.

¹¹ Head 48(3)(iii) of *Scheme of Mental Capacity Bill 2008*.

¹² Head 48(3)(ii) of *Scheme of Mental Capacity Bill 2008*, referring to Head 21.

¹³ Section 5(2)(d)(iii) of *Powers of Attorney Act 1996*.

donor understands the effect of making the EPA and that he or she has no reason to believe that the document is executed as a result of fraud or undue pressure.¹⁴ Third a registered medical practitioner must provide a statement to the effect that they are satisfied that the donor had the capacity to execute the EPA.¹⁵ Finally, once the donor loses capacity, the EPA is registered in the High Court.¹⁶

2.18 In recognition that a person with capacity has a right to appoint a person to make health care decisions in the event of his or her incapacity and in recognition of the safeguards surrounding the appointment of an EPA, the Commission has concluded that a person with full capacity should have the power to appoint a donee under an EPA to make decisions on artificial life-sustaining treatment, organ donation and non-therapeutic sterilisation. This would serve to promote autonomy which is consistent with the guiding principles in the *Scheme of Mental Capacity Bill 2008*¹⁷ and Principle 3 of the Council of Europe's *Draft Recommendation on Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity*.

2.19 The Commission is of the opinion that, because of the major implications of refusing life-sustaining treatment or consenting to non-therapeutic sterilisation or organ donation, the donor should explicitly state his or her intention to appoint an attorney to make such decisions. Thus the Commission is of the opinion that there should be a clear distinction between personal welfare decisions and the very serious implications of refusing life-sustaining treatment.

2.20 Currently, when a donor completes an EPA under the *Enduring Powers of Attorney Regulations 1996*, they must first state that he or she is granting the attorney to make decisions regarding his or her property and affairs in the event of their incapacity. The donor may then limit this power, for example, the donor may state in the EPA that the attorney may not sell his or her house. The donor is then given the option to outline any personal care decisions which he or she may wish the attorney to make in the event of his or her incapacity. The donor may then limit this decision-making power. The Commission is of the opinion that an option for the donor to grant the attorney the power to refuse life-sustaining treatment in the event of the donor's incapacity must then be contained in the EPA form. Thus, should a donor wish to grant his or her attorney the power to refuse life-sustaining treatment, a

¹⁴ Section 5(2)(d)(ii) of *Powers of Attorney Act 1996*.

¹⁵ Section 5(2)(d)(iii) of *Powers of Attorney Act 1996*.

¹⁶ Section 9 of *Powers of Attorney Act 1996*.

¹⁷ Head 1 of *Scheme of Mental Capacity Bill 2008*.

separate form should be completed by the donor and that this should be provided for in new Regulations (which are required in any event in views of the changes proposed in the Scheme of the 2008 Bill and the replacement of the 1996 Act). The donor may then specify the scope of and limits to this power, for example, the donor could state that while the attorney has the power to refuse life-sustaining treatment, the attorney may never refuse CPR.

2.21 The Commission considers that extending the power granted under an EPA to cover all healthcare decisions will enhance the autonomy of the donor and ensure that healthcare decisions are made by the attorney who is appointed by the donor under the EPA and not by the court. The Commission is of the opinion that such decisions can be made by the attorney because of the safeguards currently in place under the *Powers of Attorney Act 1996* and which are to be retained in the *Scheme of a Mental Capacity Bill 2008* which will replace the 1996 Act. Thus the Commission recommends that the Government's *Scheme of a Mental Capacity Bill 2008* be extended to provide that a person may appoint an attorney under an enduring power of attorney (EPA) to make decisions regarding life-sustaining treatment, organ donation and non-therapeutic sterilisation, provided that these are expressly provided for in the EPA.

2.22 *The Commission recommends that the Government's Scheme of a Mental Capacity Bill 2008 be extended to provide that a person may appoint an attorney under an enduring power of attorney (EPA) to make decisions regarding life-sustaining treatment, organ donation and non-therapeutic sterilisation, provided that these are expressly provided for in the EPA.*

(3) Conflict between EPAs and advance care directives

2.23 The Commission turns to consider the potential for a conflict to arise where, for whatever reason, a person has both conferred a power of attorney under the *Powers of Attorney Act 1996* and has also made an advance care directive (with or without the appointment of a health care proxy). In such a situation, the Commission recommends that, bearing in mind the formalities attached to the making of an EPA under the 1996 Act, in general the EPA should take priority over an advance care directive. Where the advance care directive has been made before the EPA, it should be ordinarily be taken that the EPA is a clear, later expression, of the person's wishes and thus should be given priority. Where an advance care directive is made after an EPA, the position is more difficult. In such a situation, the Commission recommends that there should initially be an attempt to resolve any apparent conflict informally, involving the donee of the enduring power of attorney and the relevant health care professional, and, where applicable, the health care proxy. In the absence of agreement between the parties, the Commission recommends that the matter

should be referred to the High Court (the Court of Care and Protection envisaged in the Government's *Scheme of a Mental Capacity Bill 2008*).

2.24 *The Commission recommends that, in general, in the event of a conflict between the terms of an enduring power of attorney (EPA) executed under the Powers of Attorney Act 1996 and an advance care directive, the EPA should take priority over an advance care directive. The Commission also recommends that, where it appears that a conflict arises between the terms of an EPA and an advance care directive, there should initially be an attempt to resolve any apparent conflict informally, involving the donee of the enduring power of attorney and the relevant health care professional, and, where applicable, the health care proxy. The Commission also recommends that, in the absence of agreement between the parties, the matter should be referred to the High Court for resolution.*

D Advance care directives and a health care proxy

2.25 As the Commission has noted, an advance care directive is a statement or expression of wishes by a person with capacity setting out his or her wishes regarding refusal of treatment.¹⁸ This can constitute a fully completed advance care directive (“I do not wish to have CPR continued after another stroke”) and, as already mentioned, it marks an important difference between an advance care directive and an EPA; with an EPA, a third party is always nominated by the donor to take future decisions. In some instances, of course, the maker of the advance care directive may choose to appoint a third party, often known as a health care proxy, who can make the relevant health care decisions when they actually arise

2.26 The Commission has already noted that the Government's *Scheme of a Mental Capacity Bill 2008* proposes to introduce the concept of a general authority for third parties to engage in informal decision-making in respect of personal care, health care or treatment of a person whose decision-making capacity is in doubt.¹⁹ This would be a welcome development but would be limited, in effect, to day-to-day health care matters and would not extend to the range of treatment decisions envisaged by advance care directives.

2.27 Thus, at the day-to-day end of the health care decision-making spectrum, the provisions on “general authority to act” in the Scheme of the 2008 Bill would provide third parties with an important level of authority to act legitimately within the law. At the other end of the spectrum, the proposals for an EPA would allow a person with capacity to appoint a third party with

¹⁸ See paragraph 1.82.

¹⁹ Head 16(1) of *Scheme of Mental Capacity Bill 2008*, discussed above in Part C.

extensive powers to act. The Commission considers that an advance care directive comes in between these two ends of the spectrum and is thus of the view that provision for the appointment of a health care proxy under an advance care directive remains, as indicated by the Council of Europe's draft *Recommendation on Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity*,²⁰ an important aspect of general reform of the law on mental capacity. In Chapter 3, the Commission discusses in detail the arrangements for the appointment of a health care proxy in the proposed legislative framework, including how these may affect the scope of the proxy's powers. The Commission completes this Chapter by outlining in general the different settings in which an advance care directive may arise and how this affects the extent of the proxy's proposed role.

2.28 An advance care directive may be created far in advance of the treatment matters it deals with, or it may be created in acute circumstances, such as in an accident and emergency unit of a general hospital. Due to these very different circumstances an advance care directive may sometimes not even be in writing. The Commission recognises, however, the implications for the maker of a later refusal of medical treatment. Thus, where a health care proxy is nominated in an advance care directive a number of safeguards should be in place to ensure that the wishes of the maker are followed and that appropriate precautions are in place, especially where life-sustaining treatment is involved.

2.29 The health care proxy will, of course, be appointed by the maker of the advance care directive prior to him or her losing capacity, and one precaution that arises in this respect (and reflects the principle of individual autonomy) is that it is likely the proxy will be a close friend or relative of the maker. Due to this close relationship, the proxy can "provide invaluable information about the patient's wishes in the event of incapacity and so supplement the provisions of the living will."²¹ The use of a proxy will also be of particular importance in the case of unforeseen circumstances. As the maker of an advance care directive cannot predict all possible scenarios, it has been suggested that "patients should focus on appointing as a proxy someone they trust to interpret their stated preferences or extrapolate their statements if needed."²²

²⁰ Available at www.coe.int. See paragraphs 1.35-1.38, above.

²¹ Docker "*Living Wills*" *Tolley's Finance and Law for the Older Client* STEP AT G1.21.

²² Lo and Steinbrook "Resuscitating Advance Directives" (2004) 164 *Arch Intern Med* 1501 at 1504.

2.30 Another protection of importance is that the Commission has already recommended that informed decision-making must form the basis for the proposed legislative framework on advance care directives.²³ In addition, the Commission recommends that any advance care directive involving refusal of life-sustaining treatment will have to be in writing and will only be valid if it has resulted from informed decision-making, which would often involve consulting a health care professional.²⁴ Thus, makers of advance care directives will understand the implications of future refusal of such treatment. Because of this, the Commission considers that a person should have the power to appoint a proxy to refuse life-sustaining treatment in an advance care directive. As the Commission discusses later,²⁵ an advance care directive which refuses life-sustaining treatment must be witnessed, thus the witness will ensure that the document is not created as a result of undue influence or other external influences.

2.31 *The Commission recommends that a health care proxy may be appointed under an advance care directive.*

²³ See paragraphs 1.86-1.92.

²⁴ See paragraph 3.70.

²⁵ See paragraph 3.59.

CHAPTER 3 THE DETAILED LEGISLATIVE FRAMEWORK FOR ADVANCE CARE DIRECTIVES

A Introduction

3.01 This Chapter discusses the main elements of the Commission's proposed legislative framework for advance care directives. In Part B, the Commission discusses the need to ensure that the term healthcare professional is given a wide meaning in the proposed statutory framework. In Part C, the Commission discusses how the legislative framework should deal with various health care situations, in particular basic care, palliative care, life-sustaining treatment, artificial nutrition and hydration (ANH) and 'do not resuscitate' (DNR) orders. Part D sets out the detailed requirements that the Commission recommends be in place for an advance care directive to be enforceable. In Part E the Commission discusses the detailed arrangements concerning the appointment of a health care proxy. In Part F the Commission discusses the scope of a statutory Code of Practice on Advance Care Directives that would support the legislative framework.

B Healthcare professional

3.02 The Commission has already noted in Chapter 1 that advance care directives should be seen in the wider context of healthcare planning. An advance care directive may, quite often, be drafted by a person in conjunction with a relative or friend. It is equally likely that the maker of an advance care directive would consult with a health care professional prior to making an advance care directive, and the Commission would encourage this also because it would reinforce informed decision-making. The type of professional person likely to be consulted could include a:

- doctor¹
- nurse²

¹ Regulated by the *Medical Practitioners Act 2007*.

² Regulated by the *Nurses Act 1985*.

- dentist³
- psychologist⁴
- social care worker⁵
- social worker,⁶ or
- religious adviser.

3.03 The Commission notes that a number of healthcare professionals may be involved in a healthcare decision. These could include a person's GP, a consultant, a nurse, a midwife and a religious adviser. The Commission acknowledges that a senior healthcare professional may have overall responsibility for a person's care. While this is the case, this does not prevent others being involved in the decision-making process concerning the care of the person concerned. The senior healthcare professional will ordinarily consult other members of the healthcare team before a decision is made. The Commission is aware, however, that in an emergency this may not always be possible.

3.04 Because of the team-based nature of health care today, the Commission considers that, in the context of encouraging those making advance care directives to consult with a professional adviser, it would not be appropriate to restrict this to, say, a doctor. Thus, the Commission recommends that the proposed legislative framework should include a very wide definition of the term "healthcare professional" which reflects the spiritual, emotional, psychological as well as medical approach to care that is likely to precede the making of an advance care directive.

3.05 *The Commission recommends that the legislative framework for advance care directives contains a very wide definition of healthcare professional, which includes those involved in the medical, spiritual, emotional and psychological care of a person.*

C Various health care situations and advance care directives

3.06 In this Part, the Commission discusses how the legislative framework should deal with various health care situations, in particular basic care, palliative

³ Regulated by the *Dentists Act 1985*.

⁴ Regulated by the *Health and Social Care Professionals Act 2005*.

⁵ *Ibid.*

⁶ *Ibid.*

care, life-sustaining treatment, artificial nutrition and hydration (ANH) and ‘do not resuscitate’ (DNR) orders.

(1) Basic Care

3.07 The Commission has already recommended that the proposed legislative framework should include the general principle that a person has the right to refuse medical treatment, even if the refusal is based on what appear to be irrational grounds.⁷ This general principle and right is, however, not absolute. In the Consultation Paper, the Commission provisionally recommended that an advance care directive that directs a refusal of basic care should not, for reasons of public policy, be enforceable.⁸ This view was supported during the consultation period after the publication of the Consultation Paper, and the Commission reaffirms that view in this Report. In the Commission’s view, basic care that is designed to make the patient comfortable must always be provided. In this respect, the Commission also agrees with the Law Commission of England and Wales that this limit to the scope of advance care directives would not involve a significant infringement on a person’s autonomy.⁹

3.08 During the consultation process, it was suggested that the Commission set out a complete definition of basic care in this Report. Because of rapid developments in health care and medical science, however, such a complete definition is not desirable in a legislative framework. The Commission agrees with the British Medical Association that basic care includes, but is not limited to, warmth, shelter, oral nutrition and hydration and hygiene measures.¹⁰ The Commission has therefore concluded that a broad definition of basic care could be included that will take account of the specific needs of an individual person. The Commission recommends that the proposed Code of Practice on Advance Care Directives¹¹ should contain detailed guidance for health care professionals on what constitutes basic care.

3.09 *The Commission recommends that basic care cannot be refused under an advance care directive. The Commission recommends that basic care*

⁷ See paragraphs 1.86-1.92, above.

⁸ Law Reform Commission *Consultation Paper on Bioethics: Advance Care Directives* (LRC CP 51-2008) at paragraph 1.48.

⁹ Law Commission of England and Wales *Report on Mental Incapacity* (No 231 1995) at paragraph 5.34.

¹⁰ British Medical Association *Withholding and Withdrawing Life Prolonging Medical Treatment* (3rd ed, 2007), at 15.

¹¹ See paragraph 3.117-3.120, below.

should be defined to include, but is not limited to, warmth, shelter, oral nutrition and hydration and hygiene measures. The Commission also recommends that the proposed Code of Practice on Advance Care Directives should contain detailed guidance for health care professionals on what constitutes basic care.

(2) Palliative Care

3.10 Palliative care is treatment that manages pain relief and that seeks to make a patient comfortable rather than to cure an illness. The Commission is aware that there is some disagreement as to whether palliative care forms part of basic care. In 1995, the English Law Commission recommended that care which alleviates severe pain should come within the definition of basic care.¹² The Code of Practice made under the English *Mental Capacity Act 2005* (which largely implemented the recommendations made by the Law Commission in 1995) states that care that is “needed to keep a person comfortable” is basic care.¹³ However, the Code of Practice does not mention whether pain relief or palliative care comes within this definition.

3.11 In Singapore, the *Advance Medical Directive Act 1996* states that palliative care must always be provided.¹⁴ However, palliative care is defined as

- (a) “the provision of reasonable medical procedures for the relief of pain, suffering or discomfort; and
- (b) the reasonable provision of food and water.”

3.12 The Commission is in agreement with the English Law Commission that a person should be entitled to refuse pain relief because they may prefer to remain alert. Palliative care, however, encompasses more than just pain relief. It is about ensuring that the person is comfortable when their illness becomes terminal. Due to the importance of ensuring that a person dies with dignity and in the least amount of pain possible, the Commission recommends that palliative care should be regarded as part of basic care. The Commission also recommends that the proposed Code of Practice on Advance Care Directives should include detailed guidance on what constitutes palliative care.

3.13 The Commission recommends that palliative care should be regarded as part of basic care. The Commission also recommends that the proposed Code of Practice on Advance Care Directives should include detailed guidance on what constitutes palliative care.

¹² Law Commission of England and Wales *Report on Mental Incapacity* (No 231 1995), at paragraph 5.34.

¹³ Code of Practice-*Mental Capacity Act 2005*, at paragraph 9.28.

¹⁴ Section 11 *Advance Medical Directive Act 1996* (Sing).

(3) Artificial Life-sustaining treatment

3.14 In the Consultation Paper, the Commission noted that many States have divergent approaches as to whether an advance care directive that refuses artificial life-sustaining treatment should be enforceable.¹⁵ In England and Wales, the *Mental Capacity Act 2005* defines life-sustaining treatment as “treatment which in the view of the person providing health care for the person concerned is necessary to sustain life.”¹⁶ The British Medical Association notes that a patient’s refusal of artificial life-sustaining treatment must be respected.¹⁷ Life-prolonging treatment includes “all treatment or procedures that have the potential to postpone the patient’s death and includes cardiopulmonary resuscitation, artificial ventilation, specialised treatment for particular conditions such as chemotherapy or dialysis, antibiotics when given for potentially life-threatening infection and artificial nutrition and hydration.”¹⁸

3.15 In Queensland, life-sustaining treatment is defined as “health care intended to sustain or prolong life and that supplants or maintains the operation of vital bodily functions that are temporarily or permanently incapable of independent operation.”¹⁹ Before a person can refuse life-sustaining treatment, however, their health must be in decline, the person must have a terminal illness, be in a persistent vegetative state, be permanently unconscious or have an illness from which there is no reasonable prospect of recovery.²⁰ The advance health directive will also only apply if the adult has no reasonable prospect of regaining capacity for health matters.²¹

3.16 In 2006, the Law Reform Commission of Hong Kong defined life-sustaining treatment as:

“... any of the treatments which have the potential to postpone the patient’s death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatment for particular conditions such as

¹⁵ Law Reform Commission *Consultation Paper on Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraphs 4.14-4.19.

¹⁶ Section 4(10) of the *Mental Capacity Act 2005*.

¹⁷ British Medical Association *Withholding and Withdrawing Life-Prolonging Medical Treatment* (3rd ed., 2007), at 3.

¹⁸ *Ibid*, at 5.

¹⁹ Section 5A of the *Powers of Attorney Act 1998 (Qld)*.

²⁰ Section 36(2)(a) of the *Powers of Attorney Act 1998 (Qld)*.

²¹ Section 36(2)(c) of the *Powers of Attorney Act 1998 (Qld)*.

chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration.”²²

3.17 The Commission considers that, consistent with the autonomy principle,²³ a person has the right to refuse medical treatment even if that treatment leads to death and, therefore, a person can refuse life-sustaining treatment in an advance care directive. The Commission accepts that, in general terms, artificial life-sustaining treatment is treatment which in the view of the person providing health care is necessary to sustain life. The Commission is of the opinion that to require a person to be suffering from a terminal condition before they can refuse artificial life-sustaining treatment would be unduly limiting on a person’s autonomy. The Commission recommends that artificial life-sustaining treatment may be refused in an advance care directive. The Commission recommends that an advance care directive can include a refusal of artificial life-sustaining treatment, that is, treatment which is intended to sustain or prolong life and that supplants or maintains the operation of vital bodily functions that are incapable of independent operation. The Commission accepts, however, that what constitutes artificial life-sustaining treatment in a specific case depends on the circumstances of a patient’s specific illness. The Commission therefore recommends that the Code of Practice on Advance Care Directives should include detailed guidance on the types of treatment that comes within this general definition of artificial life-sustaining treatment.

3.18 *The Commission recommends that an advance care directive may include a refusal of artificial life-sustaining treatment, that is, treatment which is intended to sustain or prolong life and that supplants or maintains the operation of vital bodily functions that are incapable of independent operation. The Commission also recommends that the proposed Code of Practice on Advance Care Directives should include detailed guidance on the types of treatment that come within the definition of artificial life-sustaining treatment.*

(a) Artificial Nutrition and Hydration (ANH)

3.19 The Commission is aware that there has been some debate as to whether artificial nutrition and hydration (ANH) constitutes life-sustaining medical treatment. The British Medical Association has defined ANH as:

“...techniques for providing nutrition and hydration that are used to bypass an inability to swallow. It includes the use of a nasogastric

²² Law Reform Commission of Hong Kong *Report on Substitute Decision-Making and Advance Directives in Relation to Medical Treatment* (2006), at paragraph 8.53.

²³ See paragraphs 1.94-1.95, above.

tube, percutaneous endoscopic gastrostomy (PEG feeding) and total parenteral nutrition.”²⁴

The Law Reform Commission of Hong Kong has defined ANH as “the feeding of food and water to a person through a tube.”²⁵

3.20 The Commission has already discussed in detail *Re Ward of Court (No 2)*,²⁶ which involved a woman in a near persistent vegetative state (near PVS). In the Supreme Court, Hamilton CJ stated that a person has a right to die a natural death and not to have life artificially maintained.²⁷ Hamilton CJ went on to note that feeding through a percutaneous endoscopic gastrostomy tube (PEG tube) cannot be regarded as a normal means of feeding.²⁸ Hamilton CJ thus found, based on the facts of that case, that the treatment was medical treatment and not merely “medical care.”²⁹ Denham J, in concurring that the provision of ANH was medical treatment, also found that the medical treatment was invasive and resulted in a loss of bodily integrity.³⁰

3.21 A debate has thus emerged about whether ANH is medical treatment or should be treated in the same way as normal food and drink. In its current Guide to Ethical Conduct and Behaviour, the Irish Medical Council states that:

“Access to nutrition and hydration remain one of the basic needs of human beings, and all reasonable and practical efforts should be made to maintain both.”³¹

²⁴ BMA *Withholding and Withdrawing Life-prolonging Medical Treatment*, 3rd ed, 2007 at 15.

²⁵ Law Reform Commission of Hong Kong *Report on Substitute Decision-Making and Advance Directives in Relation to Medical Treatment* (2006), at paragraph 8.53.

²⁶ [1996] 2 IR 79.

²⁷ *Ibid*, at 124.

²⁸ *Ibid*, at 125.

²⁹ *Ibid*.

³⁰ *Ibid*, at 158.

³¹ Irish Medical Council *A Guide to Ethical Conduct and Behaviour* (6th ed, 2004), at paragraph 22.1.

Similarly, Power argues that there is no difference between the ethical obligations of providing food to a baby or a person with a spinal injury and providing ANH.³²

3.22 It has been suggested that ANH is medical treatment as it requires medical skill in administering a tube.³³ Comparisons have also been drawn between ANH and a ventilator.³⁴ Artificial nutrition and hydration becomes necessary when a problem occurs with the digestive system in the same way that a respirator becomes necessary to ensuring the flow of oxygen around the body when lungs are impaired.³⁵

3.23 In the context of advance care directives, the Commission considers that the focus should be on the specific circumstances of the person. Thus whether artificial nutrition and hydration is classified as basic care or life-sustaining treatment will depend upon the circumstances of the case. For example, for a stroke victim who has temporarily lost the ability to swallow ANH must be considered as basic care. This type of care is necessary to keep a person comfortable and is vital to support the body's defences against disease.³⁶ Food and water should not become medical treatment merely due to the process in which it is administered. After all, "food and water do not perform the same function in the body that medical treatments do."³⁷

3.24 Where there is no possibility of recovery or where the administration of ANH would be considered invasive and providing no real improvement to the patient, ANH would be considered artificial life-sustaining treatment. In such a case, ANH is not about improving a person's condition, but merely sustaining their life artificially. As Sheperd explained:

"For people in a permanent vegetative state, tube feeding is less like these acts of common decency and more like a ventilator because the provision of nutrition and hydration through a PEG tube is not

³² Power "Bioethics and the End of Life" (2008) Bar Review 19, at 21.

³³ *Airedale NHS Trust v Bland* [1993] 1 All ER 821, at 836, per Sir Thomas Birgham MR.

³⁴ *Ibid* at 871, per Lord Goff.

³⁵ Cantor "The Permanently Unconscious Patient, Non-Feeding and Euthanasia" (1989) 15 *American Journal of Law and Medicine* 381, at 385.

³⁶ Bopp "Nutrition and Hydration for Patient's: The Constitutional Aspects" (1988-1989) 4 *Issues Law and Medicine* 3, at 43.

³⁷ *Ibid*.

about respecting the body's integrity or its appearance but solely about sustaining life."³⁸

3.25 The Commission considers that determinations of whether ANH is artificial life-sustaining treatment or basic care cannot be made without the input of a medical professional. The Commission recommends that the proposed Code of Practice on Advance Care Directives should include guidance for medical professionals and authors of advance care directives for situations in which ANH will be considered life-sustaining treatment or, as the case may be, basic care.

3.26 The Commission considers, however, that in the case of an advance care directive that includes a refusal of ANH it would not be appropriate for a health care professional to decline to implement the advance care directive merely where he or she is of the opinion that this would be contrary to the best interests of the patient or that the health care professional has a conscientious objection to the withholding of ANH. In deciding whether ANH is basic care or artificial life-sustaining treatment, the decision should be based on the health care professional's medical and professional judgment only.

3.27 *The Commission recommends that the proposed Code of Practice on Advance Care Directives should provide guidance on the circumstances in which artificial nutrition and hydration (ANH) may be considered to be basic care and, as the case may be, artificial life-sustaining treatment. In deciding whether ANH is basic care or artificial life-sustaining treatment, the decision should be based on the health care professional's medical and professional judgment only.*

(b) Do not Resuscitate Orders

3.28 As noted in the Consultation Paper, cardiopulmonary resuscitation (CPR) developed in the 1960s to become standard treatment for all patients who went into cardiac arrest.³⁹ This, in turn, gave rise to the development by health care professionals, in particular doctors, of "Do Not Resuscitate" (DNR) orders. A number of studies have been carried out in Ireland on current practice concerning CPR and DNR Orders,⁴⁰ but no national DNR guidelines exist to

³⁸ Shepherd "In Respect of People Living in a Permanent Vegetative State and Allowing them to Die" (2006) 16 *Health Matrix* 631, at 681.

³⁹ Law Reform Commission *Consultation Paper Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraph 1.40.

⁴⁰ Collins "End of Life in ICU - Care of the Dying or 'Pulling the Plug'?" (2006) 99(4) *Irish Medical Journal* 112; Fennell, Butler, Saaidin and Sheikh "Dissatisfaction with Do Not Attempt Resuscitation Orders: A Nationwide Study of Irish Consultant Physician Practices" (2006) 99(7) *Irish Medical Journal* 208.

assist either health care professionals or patients on the circumstances in which a DNR order should be put in place.

3.29 In the Consultation Paper, the Commission invited submissions on the status of DNR orders.⁴¹ Submissions received made it clear that ambiguity surrounding DNR orders have created real difficulties in health care practice. Among the problems identified in the Irish studies were that decisions on DNR orders were taken at too junior a level, that the patient was not included in the decision-making process and that there was low quality of the DNR documentation.⁴² It was also noted that consultants generally favoured discussing the order with the family of the patient but that they felt that a discussion with the patient and the family was in line with best practice.⁴³ The study found that patients who had a DNR order written on their chart had a mean age of 76 years,⁴⁴ thus indicating that older people are much more likely to be subject to a DNR order. Another study also found that doctors are less comfortable discussing DNR orders with patients than other forms of medical treatment,⁴⁵ with 43% of consultants almost never discussing resuscitation preferences in advance with a patient.⁴⁶

3.30 As the Commission has already noted, a person cannot demand specific forms of treatment, so that a doctor is under no obligation to administer CPR if he or she does not think that it is medically appropriate. The Commission notes that, on the basis of the Irish studies mentioned, a DNR decision can be, and often is, taken by a doctor without consulting the patient concerned. The Commission considers that decisions about resuscitation should, in general, be made in advance and form a part of a patient's care plan. This ensures that, where possible, the patient is involved in the decision making process. If the

⁴¹ Law Reform Commission *Consultation Paper Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraph 1.47.

⁴² Robinson and O'Neill "Communication and Documentation of Do-Not-Attempt-Resuscitation Orders in an Irish Teaching Hospital" (2005) 11(2) *Medico Legal Journal of Ireland* 60, at 60-61.

⁴³ *Ibid*, at 61.

⁴⁴ *Ibid*, at 60.

⁴⁵ Sulmasy, Sood and Ury "Physicians Confidence in Discussing Do Not Resuscitate Orders with Patients and Surrogates" (2008) 34 *Journal of Medical Ethics* 96, at 99.

⁴⁶ Fennell, Butler, Saaidin and Sheikh "Dissatisfaction with Do Not Attempt Resuscitation Orders: A Nationwide Study of Irish Consultant Physician Practices" (2006) 99(7) *Irish Medical Journal* 208, at 208.

patient does not have the capacity to make this decision, the discussion must take place with any proxy (if one is appointed).⁴⁷ The Commission considers, however, that before a DNR order is documented, appropriate consultation must take place with the patient (or their proxy). The Commission recommends that a decision regarding a DNR order must be made by the senior member of the health care team available. Such a decision must be documented in the patient's medical records. DNR orders must also be reviewed regularly and in accordance with changes to the patient's condition.

3.31 There is an obvious lack of clarity on these matters. The Commission notes that many health care institutions have in place guidelines on DNR orders. The Commission is of the opinion that national guidelines are necessary to assist health care professionals, patients and their families. The Commission recommends that the guidelines on DNR orders should be included in the statutory Code of Practice. The Commission considers that not only must assistance from the Medical Council and An Bord Altranais be sought to ensure that the guidelines conform to their ethical guidelines but that patient groups have a valuable role to play also. The Commission also recommends that the guidelines should provide that before a DNR order is made there is a consultative process, that this is documented on the patient's chart and that it is made by the most senior available member of the healthcare team.

3.32 *The Commission recommends that the Code of Practice on Advance Care Directives should contain guidelines on the process of putting in place a DNR order. The Commission also recommends that the guidelines should provide that before a DNR order is made there is a consultative process, that this is documented on the patient's chart and that it is made by the most senior available member of the healthcare team.*

D Detailed requirements for an advance care directive to be enforceable

3.33 The Commission has already recommended that the proposed legislative framework for advance care directives should be facilitative and that the detailed requirements or formalities required to make an advance care directive enforceable should be limited. This is to ensure that making an advance care directive is not unduly burdensome and that, for example, in some instances an unwritten advance care directive is enforceable. At the same time, the Commission considers that certain minimum requirements are required, for example in the case of life-sustaining treatment, to ensure the protection of vulnerable people. During the consultation period, this general

⁴⁷ On proxies, see paragraphs 2.25-CHAPTER 3E(a), above.

approach met with broad approval and it forms the basis of the following discussion of detailed requirements and associated recommendations.

3.34 The Commission discusses the following detailed issues: (1) unwritten and written advance care directives; (2) witnesses; (3) age (4) capacity; (5) informed decision-making; (6) specific tests for validity; (7) applicability to the relevant treatment; (8) revocation; (9) review; and (10) a register for advance care directives.

(1) Unwritten and written advance care directives

3.35 In the Consultation Paper the Commission provisionally recommended that both unwritten and written advance care directives should be enforceable.⁴⁸ The Council of Europe's Draft *Recommendation on Principles Concerning the Legal Protection of Incapable Adults* notes that states should consider whether advance directives should be recorded or made written if they are intended to have legal status. The Commission will now consider the status of unwritten advance care directives

(a) Unwritten advance care directives

3.36 The Commission reiterates that the proposed legislative framework for advance care directives should be facilitative and, in this respect, it is important that, subject to exceptions discussed below (notably the situation of life-sustaining treatment), an unwritten advance care directive can be enforceable. This is consistent with the Commission's view that making an advance care directive should not place an undue burden on individuals.

3.37 The Commission acknowledges that some difficulties exist with establishing the existence of an unwritten advance care directive - and perhaps even more so how it might be interpreted. These difficulties may, in some instances, prove to be intractable. At one extreme, if a spouse or partner of a patient were to say "he told me last year he would not want to be resuscitated a third time if this happened," it would be difficult to suggest that such an asserted advance care directive should be enforceable under the Commission's proposed legislative framework. The Commission notes, however, that this is not necessarily because the asserted advance care directive is a reported, unwritten, statement of wishes. Such an advance care directive would also be prone to difficulty because it was removed in time from the actual health care decision making to which it might apply and it would not be entirely clear whether it is applicable to that health care decision. For at least these two

⁴⁸ Law Reform Commission *Consultation Paper on Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraph 4.13.

reasons, which are applicable equally to a written advance care directive,⁴⁹ such an advance care directive is open to question in terms of enforceability.

3.38 By contrast, where a person has to be brought suddenly to the Accident and Emergency Department of a hospital, he or she may have thought in advance of what they would or would not like to happen to them. Such a person may have created an advance care directive or may not wish to undergo repeated resuscitation but not communicated this opposition to anyone. Such a discussion regarding treatment the person may not wish to undergo can be communicated-and indeed a person should be encouraged to discuss their wishes-when they are being admitted to hospital. The person may or may not have a spouse or partner with them and may also state very clearly that the spouse or partner has full authority to carry out these wishes on their behalf – the spouse or partner is to be their proxy decision-maker. In the Commission’s view, these clearly stated wishes, with or without the presence of a partner or spouse, should be legally enforceable under the proposed legislative scheme for advance care directives. It may very well be that these unwritten wishes will be recorded on the person’s medical chart by the health care professional involved in the admissions procedure and this written record may very well assist to clarify the scope of the advance care directive, and the role (if any) of a spouse or partner. In some instances, with the development of suitable guidance and protocols, it may be that the written record can be regarded as a written advance care directive.⁵⁰

3.39 The Commission is of the opinion that health care professionals be encouraged to discuss what a person’s wishes are and whether a person wishes to create an advance care directive. This discussion may take place upon admission or when a person is signing a consent form. Indeed best practice should dictate that hospital forms include information regarding advance care directives. While such forms should not replace the conversation between a patient and health care professional, the Commission recognises the time constraints that can occur in a medical emergency thus the information forms can be useful. However, replacing the conversation on advance care directives with the forms should only be used in limited circumstances, as good communication between health care professionals and patients is part of good health care.

3.40 Accordingly, the Commission recommends that, subject to certain exceptions discussed below (notably the situation of life-sustaining treatment), an unwritten advance care directive is enforceable under the proposed statutory framework. The Commission also recommends that the proposed Code of

⁴⁹ See paragraphs 3.93 (time factors) and 3.86 (applicability rule) below.

⁵⁰ See paragraph 3.50, below.

Practice on Advance Care Directives should include guidance on the types of circumstances in which an unwritten advance care directive would be likely to be enforceable under the proposed statutory framework.

3.41 *The Commission recommends that, subject to the situation of life-sustaining treatment, an unwritten advance care directive is enforceable under the proposed statutory framework. The Commission also recommends that the proposed Code of Practice on Advance Care Directives should include guidance on the types of circumstances in which an unwritten advance care directive would be likely to be enforceable under the proposed statutory framework.*

(b) Written advance care directives

3.42 In the Consultation Paper, the Commission provisionally recommended that an advance care directive that refuses life-sustaining medical treatment must be in writing.⁵¹ The Commission reaffirms that view in this Report, primarily because of the implications of refusing such treatment. The Commission also emphasises again that any reference to “writing” includes both manual and automated record-keeping processes.

3.43 In keeping with the view that making an advance care directive should not place an undue burden on individuals, the Commission also recommends that, where an individual chooses to prepare a written advance care directive (or is required to do so because it involves life-sustaining treatment), it need not be in a prescribed form. The Commission recommends, however, that the written advance care directive must contain some basic information, such as:

- Name, date of birth and address of the person making the advance care directive
- Name and address of the health care proxy (if any),⁵² and
- Name and address of the person’s general practitioner or other health care professional

3.44 As to the content of a written advance care directive, the Commission recommends that the proposed Code of Practice on Advance Care Directives should contain guidance on what should be included in such an advance care directive. Without being prescriptive on this, the Commission recommends that enough information should be provided to ensure that it is clear both who made

⁵¹ Law Reform Commission *Consultation Paper on Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraph 4.23.

⁵² See also paragraph 3.112, below.

the advance care directive and the type of health care treatment or treatments being refused.

3.45 As already mentioned in the context of unwritten advance care directives,⁵³ an individual may not have made a written advance care directive but will have clear views as to refusal of certain forms of treatment when a particular situation arises, such as when admitted to the Accident and Emergency Department of a hospital or in the period immediately before surgery. Where an individual communicates their wishes to a health care professional, that decision is often likely to be recorded in their medical notes and charts. The Commission considers that, where this occurs, the recorded medical notes may be regarded as a written advance care directive. It may be that there is disagreement about whether the recorded information accurately reflects the individual's wishes, in particular where the individual has not been involved in drawing up the written record. The Commission considers that this difficulty may be overcome in time through the development of good guidance on the content of advance care directives in the proposed Code of Practice on Advance Care Directives.

3.46 The Commission also considers that, in keeping with the view that making an advance care directive should not place an undue burden on individuals, other clear expressions of wishes should be deemed to be written advance care directives. These would include, for example, "no blood" cards which members of the Jehovah's Witness faith carry to state that they do not consent to blood transfusions.

3.47 To conclude this section, the Commission accordingly recommends that an advance care directive that involves a refusal of life-sustaining medical treatment must be in writing (and that "writing" includes both manual and automated record-keeping processes). The Commission also recommends that, where an individual chooses to prepare a written advance care directive (or is required to do so because it involves life-sustaining treatment), it need not be in a prescribed form but must contain certain core information, such as: name of person making the advance care directive, date of birth, address, health care proxy (if any), and name and address of general practitioner or other health care professional. The Commission also recommends that the proposed Code of Practice on Advance Care Directives should contain guidance on what should be included in the advance care directive. The Commission also recommends that a refusal of treatment recorded on a person's medical charts or notes may be deemed to be a written advance care directive and that a clear written statement in the form of for example, a 'no blood' card is deemed to be an advance care directive.

⁵³ See paragraph 3.36, above.

3.48 *The Commission recommends that an advance care directive that involves a refusal of life-sustaining medical treatment must be in writing (and that “writing” includes both manual and automated record-keeping processes).*

3.49 *The Commission recommends that, where an individual chooses to prepare a written advance care directive (or is required to do so because it involves life-sustaining treatment), it need not be in a prescribed form but must contain certain core information, such as: name of person making the advance care directive, date of birth, address, name and address of health care proxy (if any), and name and address of the person’s general practitioner or other health care professional. The Commission also recommends that the proposed Code of Practice on Advance Care Directives should contain guidance on what should be included in the advance care directive.*

3.50 *The Commission recommends that a refusal of treatment recorded on a person’s medical charts or notes may be deemed to be a written advance care directive and that a clear written statement in the form of for example, a ‘no blood’ card is deemed to be an advance care directive.*

(2) Witnesses

3.51 A number of legislative frameworks in other States require that an advance care directive be witnessed by at least one person, but the Commission notes that such requirements involve considerable variations. In England, the *Mental Capacity Act 2005* stipulates that the advance care directive must be witnessed by one person in the case of a refusal of life-sustaining medical treatment only.⁵⁴ In the Australian Capital Territory and the Northern Territory, witnesses need only attest to the fact that the person signed the directive.⁵⁵ In Queensland, South Australia and Victoria, a witness must attest to the fact that the individual had the capacity to make the directive.⁵⁶

3.52 In the Consultation Paper the Commission noted that there is some divergence over who the witness should be. The Law Reform Commission of Hong Kong recommended that one of the witnesses should be a medical practitioner as they would be able to access the capacity of the author of the advance care directive and also be able to explain the implications of the

⁵⁴ Section 22(5) of the *Mental Capacity Act 2005*.

⁵⁵ Section 4(2) of the *Natural Death Act 1988*(NT); regulation 2 of the *Natural Death Regulations 1989* (NT).

⁵⁶ Section 44(4)(b) of the *Powers of Attorney Act 1998* (Qld); section 7(2) of the *Consent to Medical Treatment and Palliative Care Act 1995* (SA); schedule 1 of the *Consent to Medical Treatment and Palliative Care Regulations 2004* (SA); section 5(1) of the *Medical Treatment Act 1988* (Vic).

advance care directive.⁵⁷ Similarly, in Singapore one of the witnesses must be a medical practitioner.⁵⁸

3.53 The Commission notes the value of requiring that a health care professional, such as a doctor, witness the signing of the advance care directive. The health care professional would be in a position to explain the implications of the advance care directive. The Commission considers, however, that to require a health care professional to witness the advance care directive is unduly burdensome on both the author of the advance care directive and the health care professional. A person may not have established a close relationship with a health care professional and may prefer a close friend or a family member to be their witness. A person may also refuse treatment in the advance care directive which may not be consistent with medical advice.

3.54 The Commission also noted that the Law Reform Commission of Hong Kong also recommended that neither of the witnesses should have an interest in the estate of the author of the advance care directive.⁵⁹ In North Dakota an advance care directive must either be notarised or signed by two witnesses, at least one of which may not be:

“...a health care or long-term care provider providing direct care to the principal or an employee of a health care or long-term care provider providing direct care to the principal on the date of execution... the agent, the principal’s spouse or heir, a person related to the principal by blood, marriage or adoption, a person entitled to any part of the estate of the principal upon the death of the principal under a will or deed in existence or by operation of law, any other person who has, at the time of execution, any claims against the estate of the principal, a person directly financially responsible for the principal’s medical care, or the attending physician of the principal.”⁶⁰

3.55 The Commission notes the concern that the witness should not be someone who will benefit, for example, under the will. Section 82(1) of the *Succession Act 1965* states:

“If a person attests the execution of a will, and any devise, bequest, estate, interest, gift, or appointment, of or affecting any property

⁵⁷ Hong Kong Law Reform Commission *Report on Substitute Decision-Making and Advance Directive in Relation to Medical Treatment*, at paragraph 8.54- 8.59

⁵⁸ Section 3(2) of the *Advance Medical Directive Act 1996* (Sing).

⁵⁹ Hong Kong Law Reform Commission *Report on Substitute Decision-Making and Advance Directive in Relation to Medical Treatment*, at paragraph 8.59.

⁶⁰ ND Cent Code § 23-06.5-05 (2005).

(other than charges and directions for the payment of any debt or debts) is given or made by the will to that person or his spouse, that devise, bequest, estate, interest, gift, or appointment shall, so far only as concerns the person attesting the execution of the will, or the spouse of that person, or any person claiming under that person or spouse, be utterly null and void.”

3.56 The rationale behind this is to avoid undue influence and coercion that the witness may exercise over the testator. A similar rationale can be seen in the specific context of legislation on advance care directives in other States.

3.57 Thus, in Singapore, Section 3(3) of the *Advance Medical Directive Act 1996* states that the witness who is not the medical practitioner must

“(a) not be a beneficiary under the patients will or any policy of insurance;

(b) have no interest under any instrument which the patient is the donor, settler or grantor;

(c) would not be entitled to an interest in the estate of the patient on the patient’s death intestate;

(d) would not be entitled to an interest in the moneys of the patient held in the Central Provident Fund or other provident fund on the death of that patient.”

3.58 The Commission has considered the witnessing requirement in detail. On balance, the Commission has decided not to recommend that there be a specific category of witnesses. While it is preferable that advance care directives are witnessed by an independent person, the Commission considers that to make such a condition mandatory in all situations could result in rendering advance care directives invalid for what may be, in effect, a technical error. Such an outcome would not be consistent with the general facilitative purpose of the proposed legislative framework. In the particular case of an advance care directive that involves the refusal of life-sustaining treatment, the Commission has, however, concluded that this should be witnessed by at least one person. It is likely that this could be a health care professional, such as a GP, but the Commission does not consider that this should be mandatory.

3.59 *The Commission recommends that an advance care directive which involves the refusal of life-sustaining treatment must be witnessed by at least one person.*

(3) Age

3.60 In the Consultation Paper the Commission noted that while 18 is regarded as the age of majority, section 23(1) of the *Non-Fatal Offences Against the Person Act 1997* states that a child aged 16 may consent to medical

treatment.⁶¹ The 1997 Act does not, however, expressly state that a child aged 16 may refuse medical treatment. In the Consultation Paper, the Commission invited submissions on the age a person must be before they can make a valid advance care directive.⁶² Since then, the Commission has begun a project dealing specifically with consent to medical treatment by those under the age of 18,⁶³ on which it intends to publish Consultation Paper by the end of 2009. In view of this, the Commission proposes to limit its recommendations in this Report to persons aged 18 years and will address those under 18 years in the separate project mentioned.

3.61 *The Commission recommends that, for the time being, the legislative framework should apply only to those aged 18 years or more.*

(4) Capacity

3.62 In its 2006 *Report on Vulnerable Adults and the Law*, the Commission recommended that there should be a presumption of capacity for those aged 18 years and over in its proposed general legislative reform of the law on mental capacity.⁶⁴ This recommendation was incorporated into the Government's *Scheme of a Mental Capacity Bill 2008* which proposes that there be a general presumption of mental capacity for a person aged 18 years of age.⁶⁵ The Commission welcomes this presumption and recommends that, to avoid any doubt, this should expressly apply to the makers of advance care directives. Thus there would be the rebuttable presumption that the author of the advance care directive had the capacity to make the directive.

3.63 In *Fitzpatrick v FK*,⁶⁶ Laffoy J noted that it would be helpful if guidelines were published that specifically addressed how capacity to give a valid refusal to medical treatment is to be assessed. She added that such guidance should include "the issues which may arise relating to the giving effect to advance directives to refuse medical treatment."

⁶¹ Law Reform Commission *Consultation Paper Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraph 3.37.

⁶² Law Reform Commission *Consultation Paper Bioethics: Advance Care Directives* (LRC CP 51-2008), at 3.52.

⁶³ *Third Programme of Law Reform 2008-2014*, Project 26.

⁶⁴ Law Reform Commission *Report Vulnerable Adults and the Law* (LRC 83-2006), at paragraph 2.39.

⁶⁵ Head 1 of *Scheme of Mental Capacity Bill 2008*.

⁶⁶ [2008] IEHC 104 High Court (Laffoy J) 25 April 2008.

3.64 The Commission concurs with the view expressed in the *Fitzpatrick* case by Laffoy J that guidelines are needed to assist medical professionals when dealing with the capacity of a person to refuse medical treatment. Head 39 of the *Scheme of a Mental Capacity Bill 2008* proposes to give the Office of Public Guardian the power to create codes. Such codes include, but are not limited to, guiding health care professionals on the assessment of capacity and guiding health care professionals and those who can make informal decisions. The Commission notes that the Scheme of the 2008 Bill envisages that the Public Guardian must consult with the Health Service Executive, the Mental Health Commission, the Health Information and Quality Authority and with representatives of professional bodies in the healthcare sector and healthcare professionals when drafting codes concerning health care. The Commission considers that this would also be a suitable consultative process in the context of the Commission's proposed Code of Practice on Advance Care Directives.

3.65 *The Commission recommends that the rebuttable presumption of mental capacity in the Government's Scheme of a Mental Capacity Bill 2008 should expressly apply to the maker of an advance care directive. The Commission also recommends that the proposed Code of Practice on Advance Care Directives should include guidance on the approach to the assessment of the capacity of an individual in this context.*

(5) Informed decision making

3.66 As the Commission has noted in Chapter 1, Informed consent is one of the most important principles to have developed in medical law in recent decades. In its 2005 *Consultation Paper on Vulnerable Adults and the Law: Capacity*, the Commission noted that if medical treatment is carried out without informed consent this may be in breach of existing civil liability law, the Constitution and the European Convention on Human Rights.⁶⁷ In its current Guide to Ethical Conduct and Behaviour the Irish Medical Council notes that:

“Informed consent can only be obtained by a doctor who has sufficient training and experience to be able to explain the intervention, the risks and benefits and the alternatives. In obtaining the consent the doctor must satisfy himself/herself that the patient understands what is involved by explaining in appropriate terminology. A record of this decision should be made in the patient's notes.”⁶⁸

⁶⁷ Law Reform Commission *Consultation Paper on Vulnerable Adults and the Law: Capacity* (LRC CP 37-2005), at paragraph 7.08.

⁶⁸ Irish Medical Council *A Guide to Ethical Conduct and Behaviour* (6th ed 2004), at paragraph 17.1.

As the Commission has already noted, Denham J in *Re a Ward of Court (No 2)*⁶⁹ stated that a person can refuse medical treatment for any reason, rational or irrational. Similarly in *Re MB*⁷⁰ Butler-Sloss LJ stated that a “mentally competent patient has an absolute right to refuse to consent to medical treatment for any reason, rational or irrational, or for no reason at all, even where that decision may lead to his or her own death.”⁷¹ Both Denham J and Butler-Sloss LJ were silent on whether this right to refuse medical treatment meant that informed consent was not necessary. The Commission also notes the views of Munby J in *HE v A Hospital NHS Trust*⁷² that where “life is at stake, the evidence must be scrutinised with especial care.”⁷³

3.67 The Commission recognises the value of discussing an advance care directive with a medical professional. Medical professionals can correct misunderstandings, thus giving people more realistic insights into their prognosis.⁷⁴ The Commission notes that in *In re a Ward of Court (No.2)*⁷⁵ Denham J expressly stated that a person is entitled to make an irrational decision, including one that is in conflict with medical advice. Similarly the Government’s *Scheme of a Mental Capacity Bill 2008* states that “a person is not to be treated as unable to make a decision merely because he or she makes an unwise decision.”⁷⁶ A person’s refusal of medical treatment may be for personal reasons, and to require that a person must consult with a medical professional could be unduly burdensome as well as costly. Indeed, as the Commission noted in the Consultation Paper, requiring that a person consult with a medical professional could “lead to a tick the box situation and fail to reflect an individual’s autonomy.”⁷⁷

3.68 In the Consultation Paper, the Commission provisionally recommended that a person must consult with a medical professional if their

⁶⁹ [1996] 2 IR 79.

⁷⁰ [1997] 2 Fam Law R 426.

⁷¹ *Ibid*, at 432.

⁷² [2003] 2 FLR 408.

⁷³ *Ibid*, at paragraph 24.

⁷⁴ La and Steinbrook “Resuscitating Advance Directives” (2004) 164 *Arch Intern Med* 1501.

⁷⁵ [1996] 2 IR 97.

⁷⁶ Head 1 of *Scheme of Mental Capacity Bill 2008*.

⁷⁷ Law Reform Commission *Consultation Paper Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraph 3.14.

advance care directive involves a refusal of life-sustaining treatment.⁷⁸ During the consultation period it was noted that this requirement may be unduly burdensome on the author of the advance care directive. It could also conflict with the principle that many people refuse medical treatment for reasons other than medical, or rational, reasons.⁷⁹

3.69 The Commission emphasises that informed decision-making should be encouraged in the context of the proposed legislative framework.⁸⁰ Having considered the submissions received on this, the Commission accepts that the emphasis should be on ensuring that a person understands what treatment they are refusing and the implications of that decision,⁸¹ not who or where they get the information from. The important point is that the decision is an informed decision. Thus, the Commission has concluded that it should recommend that authors of advance care directives should be *encouraged* to consult with a health care professional when making the advance care directive rather than that this be a mandatory requirement.

3.70 *The Commission recommends that makers of advance care directives should be encouraged to consult with a health care professional. In the case of advance care directives refusing life-sustaining medical treatment, the Commission recommends that the decision must be an informed decision.*

(6) Specific requirements for the validity of an advance care directive

3.71 In the Consultation Paper the Commission provisionally recommended that an advance care directive will not be valid if:

- “The author of the advance care directive did not have the capacity at the time of its creation
- The creation of the advance care directive was not a voluntary act of the author
- If the author changed their mind and communicated this change of mind

⁷⁸ Law Reform Commission *Consultation Paper Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraph 3.15.

⁷⁹ As noted by Denham J in *Re a Ward of Court (No 2)* [1976] 2 IR 79 at 160. Similarly in *Fitzpatrick v FK*, Laffoy J noted that a person may refuse treatment on religious grounds. However in that case, Ms K did not have the capacity to make such a refusal. [2008] IECH 104.

⁸⁰ See paragraph 1.92.

⁸¹ *Ibid.*

- If a written advance care directive refusing life-sustaining medical was not witnessed and the person did not consult with a medical professional⁸²

3.72 The Commission recommends that there should be a rebuttable presumption that a person had the capacity to make an advance care directive.⁸³ Thus there will be a need for clear and convincing evidence to prove that the maker of the advance care directive did not have capacity to make the advance care directive. Such evidence can come from a witness (if one was present), the health care proxy (if one is appointed) or family and close friends.

3.73 In its 2006 *Report on Vulnerable Adults and the Law*, the Commission recommended that a functional test of capacity should be included in the proposed statutory legislative framework in mental capacity.⁸⁴ The result of this test is that a person may have the capacity to make an advance care directive which refuses an amputation but may not have the capacity to make an advance care directive which refuses life-sustaining treatment. If reasonable doubt exists, however, that the maker of the advance care directive did not have the capacity to make the advance care directive which refuses life-sustaining treatment, that doubt must be resolved in favour of preserving life.⁸⁵

3.74 An advance care directive which is not the voluntary action of the maker cannot be valid. In *Re T*,⁸⁶ the English Court of Appeal held that a patient who was 34 weeks pregnant and who had refused a blood transfusion, had been subjected to the undue influence of her mother, a Jehovah's Witness. The court held that the hospital was justified in administering the blood transfusion. Staughton LJ did warn however that for an advance directive to be invalid, there must be "such a degree of external influence as to persuade the patient to depart from her own wishes."⁸⁷ The Commission is of the opinion that an advance directive which is created as a result of undue influence is invalid.

3.75 In *Fitzpatrick v FK (No 2)*,⁸⁸ Laffoy J stated that before a refusal of treatment is valid, the refusal must be voluntary. Laffoy J stated that it was

⁸² Law Reform Commission *Consultation Paper Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraph 4.40.

⁸³ See paragraph 3.65.

⁸⁴ *Report on Vulnerable Adults and the Law* (LRC 83-2006), at paragraph 3.23.

⁸⁵ See paragraph 1.101-1.106.

⁸⁶ [1992] 4 All ER 649.

⁸⁷ *Ibid*, at 669.

⁸⁸ [2008] IEHC 104.

beyond question that a court or a doctor must be satisfied that a person's will was not overborne to such an extent that the refusal of medical treatment did not represent "a true decision" of the person. Laffoy J did state that in a particular case it may be possible that an advance care directive to refuse a blood transfusion was executed due to peer pressure as a result of membership of the Jehovah's Witness Church or fear of social or economic deprivation due to disfellowship or disassociation. Laffoy J, however, was of the opinion that such factors would have to be specifically pleaded before the court could give regard to such factors and that there would have to be evidence that the decision was not voluntary. While the issue was not raised in this case, Laffoy J did note that Ms K's decision was not motivated by fear of economic deprivation.

3.76 The Commission has recommended that while a person should be encouraged to consult with a health care professional, this is not obligatory.⁸⁹ The Commission notes that informed decision-making should underpin the proposed legislative framework. However the Commission reiterates its position that makers of health care directives should be encouraged to discuss their advance care directives with a health care professional.

3.77 *The Commission recommends that an advance care directive will be valid where*

- *The author of the advance care directive had capacity at the time of its making*
- *The making of the advance care directive was the voluntary act of the author, and*
- *The maker has not communicated alteration or withdrawal of the refusal of treatment contained in the advance care directive.*

(7) *The applicability of an advance care directive to specific treatment*

In the Consultation Paper, the Commission provisionally recommended that an advance care directive will not be applicable if:

- "It is ambiguous to the proposed treatment
- If all the circumstances outlined in the advance care directive are not present
- If, while competent, the author of the advance care directive said or did anything which puts reasonable doubt in the mind of the doctor that the

⁸⁹ See paragraph 3.70.

author had changed their mind but did not have the opportunity to revoke the advance care directive.”⁹⁰

3.78 Section 24 of the English *Mental Capacity Act 2005* states that the advance decision must relate to a “specified treatment.” This treatment, however, can be expressed in lay terms.⁹¹ The Code of Practice for the *Mental Capacity Act 2005* states that when deciding whether the advance care directive applies to the proposed treatment, health care professionals must consider:

- “how long ago the advance decision was made, and
- whether there have been changes in the patient’s personal life (for example, the person is pregnant, and this was not anticipated when they made the advance decision) that might affect the validity of the advance decision, and
- whether there have been developments in medical treatment that the person did not foresee (for example, new medications, treatment or therapies).”⁹²

3.79 The Commission agrees with the approach of the *Mental Capacity Act 2005*. Clarity is of utmost importance to ensure that medical professionals are clear as to what treatment is being refused, thus ensuring that an advance care directive is not determined to be inapplicable for ambiguity. Therefore, an advance care directive which stated “I do not want life-sustaining treatment” would not be “applicable” in this sense because the particular life-sustaining treatment has not been specified.

3.80 The Commission provisionally recommended in the Consultation Paper that an advance care directive will be inapplicable if the author of the advance care directive did or said anything which would put reasonable doubt in the mind of a doctor that the author had changed his or her mind. The Commission notes that the Council of Europe’s Draft *Recommendation on Principles Concerning the Legal Protection of Incapable Adults* specifies that member states should take into consideration situations where there is a substantial change of circumstance. The Commission accepts that a change of circumstance could render an advance care directive inapplicable. Having considered submissions received on the limited scope of the provisional recommendation which referred to “doctor”, the Commission accepts that a

⁹⁰ Law Reform Commission *Consultation Paper Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraph 4.43.

⁹¹ Section 24 of *Mental Capacity Act 2005*.

⁹² Code of Practice for *Mental Capacity Act 2005*, at paragraph 9.43.

close relationship that can exist between a patient and other health care professionals. Thus this proviso should not be limited to doctors but extend to all health care professionals, as widely defined in this Report.

3.81 The Commission noted in the Consultation Paper that a similar provision in the *English Mental Capacity Act 2005* has been criticised as being “potentially remarkably expansive.”⁹³ In the Consultation Paper the Commission discussed *HE v A Hospital Trust*.⁹⁴ Although decided before the enactment of the *Mental Capacity Act 2005*, it illustrates the potential problem of this section. In this case, a 24-year-old Jehovah’s Witness, who had been born a Muslim, required a life-saving blood transfusion. Despite having previously written an advance directive stating that she refused to consent to a blood transfusion “in any circumstances,” her father applied to court for the blood transfusion to be administered. Her father stated that his daughter had recently become engaged to a Muslim, had promised to convert to that faith and no longer attended meetings of the Jehovah’s Witness. His daughter also had admitted herself to a hospital shortly before her collapse and had made no reference to being a Jehoavh’s Witness and to having objections to blood transfusions. However the advance directive was only two years old and his daughter had made no attempt to rescind it.

3.82 Munby J set out the predicament stating that while:

“...too ready a submission to speculative or merely fanciful doubts will rob advance directives of their utility and may condemn those who in truth do not want to be treated to what they would see as indignity or worse, ...too sceptical a reaction to well-founded suggestions that circumstances have changed may turn an advance directive into a death warrant for a patient who in truth wants to be treated.”⁹⁵

3.83 Munby J however held that “the continuing validity and applicability of the advance directive must be clearly established by clear and convincing evidence.” Munby J concluded that in the circumstances the advance directive:

“...cannot have survived her deliberate, implemented decision to abandon that faith and revert to being a Muslim. When the entire substratum has gone, and when the very assumption on which the

⁹³ Law Reform Commission *Consultation Paper Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraph 4.41.

⁹⁴ [2003] 2 FLR 408.

⁹⁵ *Ibid* at 415.

advance directive was based has been destroyed by subsequent events then...the refusal ceases to be effective.”⁹⁶

3.84 Questions arose in submissions made to the Commission during the consultation process as to what is meant by “reasonable doubt” and by whom this is determined. The Commission considers that if reasonable doubt exists, this should be discussed with all individuals involved in the care of the person. This would include, but not be limited to, doctors, nurses and a proxy (if one has been appointed). The Commission is concerned that this provision should not be abused and a high threshold of doubt must be satisfied before the advance care directive is not followed, as it must be seen as the most authoritative indication of a person’s wishes.⁹⁷ Thus there must be a radical change in circumstances to render the advance care directive inapplicable. The Commission accordingly recommends that the Code of Practice provide guidance to medical profession regarding the circumstances in which reasonable doubt would render the advance care directive inapplicable.⁹⁸

3.85 Section 26(4) of the English *Mental Capacity Act 2005* provides that the Court of Protection has the power to make a declaration as to whether an advance decision exists, is valid and is applicable to a treatment. The Commission is of the opinion that if there is uncertainty regarding an advance care directive, ultimate authority to interpret the advance care directive must reside with a court. In this respect the Commission also notes that the Government’s *Scheme of a Mental Capacity Bill 2008* proposes to confer decision-making authority on the High Court, using the proposed title “the Court of Care and Protection.” While the Scheme of the 2008 Bill also proposes to confer some jurisdiction on the Circuit Court, the Scheme proposes to reserve certain decisions to the High Court, including those concerning end of life. The Commission considers that, in order to ensure that there is consistency in the context of recommending that the legislative framework on advance care directives be placed within the Scheme of the 2008 Bill, the High Court would also be the appropriate court to deal with issues concerning advance care directives. The Commission accordingly recommends that the High Court be powered to determine whether an advance care directive exists, whether it is valid and whether it is applicable to the relevant treatment under consideration.

⁹⁶ [2003] 2 FLR 408, at 422.

⁹⁷ See Maclean “Advance Directives and the Rocky Waters of Anticipatory Decision-Making” (2008) 16 (1) *Medical Law Review* 1 for analysis of this point and *HE v An Hospital Trust*.

⁹⁸ See also paragraphs 1.101-1.106.

3.86 *The Commission recommends that an advance care directive will be applicable if*

- *The treatment is the treatment specified in the advance care directive*
- *All the circumstances outlined are present*
- *While competent, the author of the advance care directive said or did nothing which puts reasonable doubt in the mind of the health care professional that the author had changed their mind but did not have the opportunity to revoke the advance care directive.*
- *If the advance care directive is ambiguous, there will be a presumption in favour of the preservation of life.*

3.87 *The Commission recommends that the High Court be empowered to determine whether an advance care directive exists, whether it is valid and whether it is applicable to the relevant treatment under consideration.*

(8) Revocation

3.88 In the Consultation Paper, while the Commission provisionally recommended that certain formalities in the creation of an advance care directive should apply, the Commission also provisionally recommended that an informal revocation should be sufficient to revoke the advance care directive.⁹⁹ The Commission agrees with the view that to require a formal revocation may mean that “a person is unable to effect change for procedural reasons” thus depriving a person of their autonomy.¹⁰⁰ The Commission would favour the approach taken in Singapore that an advance care directive may be revoked in writing, orally or “in any other way in which the patient can communicate.”¹⁰¹ The Commission emphasises that the person must, of course, have the capacity to revoke the advance care directive at the time of revocation.

3.89 *The Commission recommends that a competent person can verbally revoke their advance care directive regardless of whether there is a verbal or written advance care directive.*

(9) Review

3.90 In the Consultation Paper, the Commission provisionally recommended that, while an advance care directive should be reviewed

⁹⁹ See Law Reform Commission *Consultation Paper Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraphs 4.69-4.76.

¹⁰⁰ Maclean “Advance Decisions and the Rocky Waters of Anticipatory Decision-Making” [2007] *Medical Law Review* 1, at 12.

¹⁰¹ Section 7(1) of the *Advance Medical Directive Act 1996* (Singapore).

regularly, there should be no specific time limit put on its validity.¹⁰² The Commission recognises that an advance care directive made 30 years previously is unlikely to be “applicable” in the sense already discussed and, more significantly, runs great risks that it does not represent the views of the person. Nonetheless, the Commission concluded that a specific time limit on an advance care directive may appear arbitrary.

3.91 The Commission recognises that a person’s treatment preferences may change over time and that the advance care directive may not be updated to reflect the changes in their preferences.¹⁰³ The Commission also recognises that an advance care directive created when a person is 25 years of age may not accurately reflect a person’s preferences when they are 60.

3.92 The Commission remains of the view, however, that to have a mandatory provision for review would place an undue burden and expense on the author of an advance care directive.¹⁰⁴ The Commission has concluded that the appropriate manner to deal with this is in the proposed Code of Practice on Advance Care Directives, which should contain a recommendation that they are reviewed regularly. The Commission also recommends that while a lapse of time will not automatically invalidate the advance care directive, a health care professional may take into consideration the lapse of time between the creation of the advance care directive and its activation.

3.93 *The Commission recommends that the proposed Code of Practice on Advance Care Directives should recommend that advance care directives are reviewed regularly, but that there should be no specific time limit put on the validity of advance care directives. The Commission also recommends, however, that a health care professional may take into consideration the lapse of time between the making of an advance care directive and its activation.*

(10) A register of advance care directives

3.94 The Code of Practice for the English *Mental Capacity Act 2005* notes that it is the responsibility of the author of the advance care directive to ensure that health professionals are aware of their advance care directive. The code also recommends that family and friends should be made aware of the advance

¹⁰² Law Reform Commission *Consultation Paper Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraph 4.84.

¹⁰³ Dresser “Precommitment: A Misguided Strategy for Securing Death With Dignity” (2003) 81 *Texas Law Review* 1823, at 1835.

¹⁰⁴ Law Reform Commission *Consultation Paper Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraph 4.83.

care directive.¹⁰⁵ The Commission has already noted that many advance care directives may not be in writing, but agrees that the maker should communicate their wishes to family, friends and health care professionals. In the United States of America, when an advance care directive is registered through a healthcare provider it is stored in the US Living Wills Registry.¹⁰⁶ In Singapore, an advance care directive must be registered as a health provider is prohibited from acting on an unregistered directive.¹⁰⁷ In Denmark, a physician is obliged to check the national Living Will Data Bank (Livstestamenteregistret) before life-prolonging treatment is commenced.¹⁰⁸

3.95 The Commission notes that the Department of Health and Children has been involved in public consultation on a proposed *Health Information Bill*. The main purposes of the Bill would be to:

- introduce a Unique Health Identifier;
- support the establishment of population registers;
- clarify the legal and ethical rules on the use and disclosure of health care information; and
- define “personal health information”¹⁰⁹

Thus the Bill could include requirements that would be consistent with the concept of the storage of advance care directives in a register. This central system could be managed by the proposed Office of Public Guardian or by a non-statutory body such as the Irish Hospice Foundation. Such a system would be particularly relevant to written advance care directives. At the time of writing (September 2009), it remains unclear when the proposed *Health Information Bill* will be published or enacted. The Commission considers, nonetheless, that the principle of establishing a register of advance care directives would be very much in the interests of all involved, the maker, the health care proxy (if any) and all health care professionals. In the absence of a *Health Information Act* that might include such a register, the Commission considers that it would be feasible to begin the process of developing a less formal register of advance care directives, and that suitable guidance on its development could be given in the proposed Code of Practice on Advance Care Directives.

¹⁰⁵ *Mental Capacity Act 2005-Code of Practice*, at paragraph 9.38.

¹⁰⁶ See www.livingwillregistry.com.

¹⁰⁷ Section 5(3) of the *Advance Medical Directive Act 1996* (Singapore).

¹⁰⁸ Section 4 of §26 of the *Health Act 2005*.

¹⁰⁹ For more on the Health Information Bill see <http://www.dohc.ie/issues/hib/synopsis.pdf?direct=1>

3.96 *The Commission recommends the establishment of a register of advance care directives, especially those which must be in writing under the proposed statutory framework, and that suitable guidance on its development could be given in the proposed Code of Practice on Advance Care Directives.*

E Detailed issues concerning the healthcare proxy

3.97 In Chapter 2, the Commission recommended that a person who has validly made an advance care directive may appoint a health care proxy, a third party who will make decisions for the maker of the advance care directive. The healthcare proxy is likely to be a close friend or relative of the advance care directive. Due to this close relationship, the proxy can “provide invaluable information about the patient’s wishes in the event of incapacity and so supplement the provisions of the living will.”¹¹⁰ A proxy is also of particular use in the case of unforeseen circumstances. The maker of an advance care directive cannot predict all possible scenarios. Thus it has been suggested that “patients should focus on appointing as a proxy someone they trust to interpret their stated preferences or extrapolate their statements if needed.”¹¹¹ In this Part, therefore, the Commission turns to discuss some detailed elements concerning the appointment and powers of a health care proxy.

(a) Powers of the proxy

3.98 It has been argued that the proxy is “not the legally empowered decision-maker.”¹¹² While the proxy may provide clarity to an advance care directive, this will depend upon the quality of discussion between the maker of the advance care directive and the proxy. If the proxy has the power to decide on medical treatment which is not contained in the advance care directive, the maker of the advance care directive may not have covered this particular medical treatment. Thus the proxy will be making a decision based on what they *think* the maker of the advance care directive would want rather than what they actually do want.

3.99 In Queensland, questions were raised about the value of an enduring power of attorney appointed under a health directive. It was queried how much clarity an attorney can provide. In other words, is the attorney merely clarifying

¹¹⁰ Docker “*Living Wills*” *Tolley’s Finance and Law for the Older Client* STEP at G1.21.

¹¹¹ Lo and Steinbrok “Resuscitating Advance Directives” (2004) 164 *Arch Intern Med* 1501 at 1504.

¹¹² Docker “*Living Wills*” *Tolley’s Finance and Law for the Older Client* STEP, at G1.21.

the wishes or making their own decision.¹¹³ When discussing powers of attorney, the Scottish Law Commission stated:

“We tend to think that a better approach is that doctors should be obliged to discuss proposed treatment with the patient’s attorney. While they should give due weight to the views expressed they should not be bound by them. The overall interests of patients would be better served by a flexible system in which the professional judgment of doctors continues to have a major role.”¹¹⁴

3.100 Under the Code of Practice for the English *Mental Capacity Act 2005*, a person appointed under a lasting (enduring) power of attorney can only consent to or refuse life-sustaining treatment on behalf of the donor where the donor has specifically stated that they want the donor to have this authority.¹¹⁵ The Commission considers, however, that due to the importance of promoting patient autonomy, the proxy must have the power to refuse life-sustaining medical treatment.

3.101 The Commission is of the opinion that as the proxy is likely to be a close friend or relative with whom the maker of the advance care directive has discussed the advance care directive with, they can decide on how much decision making power the proxy should have. The Commission also notes that the quality of discussion between the maker of the advance care directive and a proxy will depend on the relationship between them and also the time available to have such a discussion.

3.102 The Commission emphasises the important distinction to be drawn between general or limited powers for a proxy. An advance care directive that appoints a proxy may confine their decision-making power to certain limited situations. This may be to ensure that the proxy will provide clarity to the advance care directive in the case of ambiguities. On the other hand, the proxy may be given general power to refuse medical treatment, including treatment which is not stated in the advance care directive. The Commission, however, notes that due to the serious consequences involved in refusing artificial life-sustaining medical treatment,¹¹⁶ the advance care directive must explicitly confer the power to refuse artificial life-sustaining treatment on the proxy.

¹¹³ Willmott, White and Howard “Refusing Advance Refusals: Advance Directives and Life-Sustaining Medical Treatment (2006) 30 *Melb. U. L. Rev.* 211 at 232.

¹¹⁴ Scottish Law Commission *Mentally Disabled Adults: Legal Arrangements for Managing their Welfare and Finances* (Discussion Paper No. 94 1991), at 5.116.

¹¹⁵ Code of Practice-*Mental Capacity Act 2005*, at paragraph 7.30.

¹¹⁶ See paragraphs 3.14-3.32.

3.103 As there will be times when the health care professional and the proxy may conflict, the Commission recommends that the proposed Code of Practice on Advance Care Directives should contain guidance on how this matter may be resolved.

3.104 *The Commission recommends that the maker of an advance care directive can confer a limited power on the maker of an advance care directive which can be*

- *Ensuring that the wishes of the maker of the advance care directive are carried out*
- *Consultation with a health care professional if there is ambiguity in the advance care directive*

3.105 *The Commission recommends that the maker of an advance care directive can confer a general power to refuse health care decisions on a health care proxy, except artificial life-sustaining treatment.*

3.106 *The Commission recommends a health care proxy will not have the power to refuse artificial life-sustaining treatment unless the advance care directive explicitly states that the health care proxy has such a power.*

3.107 *The Commission recommends the proposed Code of Practice on Advance Care Directives should include guidance on resolving any disputes between a healthcare proxy and a health care professional.*

(2) Unwritten and written advance care directives

3.108 The Commission has recommended that an advance care directive can, in general, take an unwritten or written form.¹¹⁷ The Commission notes that an advance care directive appointing a proxy can be made in the context of emergency situations. Thus to require such an advance care directive to be written would be unduly restrictive.

3.109 If, however, an advance care directive that includes the appointment of a healthcare proxy is written, the Commission recommends that the advance care directive should include

- Name of the proxy
- Address of the proxy

3.110 An advance care directive which grants the health care proxy the power to refuse artificial life-sustaining treatment must be contained in a written advance care directive. The maker of the advance care directive must state whether the health care proxy has a general power to refuse artificial life-

¹¹⁷ See paragraph 3.41.

sustaining treatment or whether the powers of the health care proxy are limited to refusing certain types of artificial life-sustaining treatment only. Thus, the Commission recommends that due to the serious implications of granting the health care proxy the power to refuse artificial life-sustaining treatment, the maker of an advance care directive must explicitly state in a written advance care directive that they are granting the health care proxy the power to refuse artificial life-sustaining treatment and outline the scope of that power.

3.111 *The Commission recommends that an advance care directive that includes the appointment of a proxy may be unwritten or written.*

3.112 *The Commission recommends that the maker of an advance care directive must explicitly state in a written advance care directive that they are granting the health care proxy the power to refuse artificial life-sustaining treatment and outline the scope of that power.*

3.113 *The Commission recommends that a written advance care directive appointing a proxy must contain*

- *Name of the proxy*
- *Address of the proxy*

(3) Discussion between maker and proxy

3.114 The Commission has recommended that one of the functions of the proxy is to consult with a health care professional if there is any ambiguity in the advance care directive. To fulfil this role, the healthcare proxy and the maker of the advance care directive must discuss the advance care directive in detail. While the maker of the advance care directive and the proxy cannot foresee all potential situations, a detailed discussion can ensure that the proxy understands the advance care directive and help resolve any ambiguity that could arise in the advance care directive. The Commission notes however that as many advance care directives appointing a proxy may be made in an emergency situation, to require a discussion between the proxy and the maker of an advance care directive to take place before the proxy has been validly appointed would be unduly burdensome. The Commission therefore recommends that the maker of the advance care directive and the proxy should be encouraged to discuss the advance care directive.

3.115 *The Commission recommends that the maker of the advance care directive and the proxy should be encouraged to discuss the advance care directive.*

(4) Relationship

3.116 Submissions received by the Commission during the consultation process raised the possibility of preventing those benefiting under a will from acting as a proxy. While the Commission understands the motivation behind

such a suggestion, the Commission considers that such an exclusion is not desirable. A proxy who is a close friend or relative of the maker of the advance care directive is more likely to be comfortable discussing the issues surrounding an advance care directive with the maker of the advance care directive. The Commission believes that this discussion is very important in the ensuring that the proxy understands the advance care directive. Thus the Commission does not make any recommendation limiting the categories of persons who can and cannot be a proxy.

F Code of Practice

3.117 In the Consultation Paper the Commission recommended drafting a Code of Practice to complement the statutory framework.¹¹⁸ The Commission is of the opinion that due to the complex issues involved, such a Code of Practice is necessary for guidance. The Commission notes that the Code of Practice for the English *Mental Capacity Act 2005* has greatly facilitated the development of detailed guidance on the general principles in the 2005 Act. The Commission notes that such a code can respond more quickly than primary legislation to developments in health care practice. Under the *Mental Capacity Act 2005*, failure to follow the Code may be taken into account in any criminal or civil proceedings.¹¹⁹

3.118 In the 2006 *Report on Vulnerable Adults and the Law* the Commission recommended the establishment of an Office of Public Guardian. One of the functions of the Office would be the preparation of codes of practice in matters of capacity.¹²⁰ The Commission recommended that the Office of Public Guardian consult with other professional bodies in the development of such codes of practice.¹²¹ The Government's *Scheme of a Mental Capacity Bill 2008* proposes to implement this recommendation and provides that the Office of Public Guardian would be empowered to issue codes of practice

- (a) "for the guidance of persons, including healthcare professionals, assessing whether a person has capacity in relation to any matter

¹¹⁸ Law Reform Commission *Consultation Paper Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraph 2.48.

¹¹⁹ Section 42(5) of *Mental Capacity Act 2005*.

¹²⁰ Law Reform Commission *Report on Vulnerable Adults and the Law* (LRC 83-2006), at paragraph 2.60

¹²¹ *Ibid.*

- (b) for the guidance of persons, including health care professionals, assessing whether a person has capacity in relation to any matter
- (c) for the guidance of the enduring powers of attorney
- (d) for the guidance of personal guardians appointed by the court
- (e) for the guidance of health care personnel as respect the circumstances in which urgent treatment may be carried out without the consent of an adult patient who lacks the capacity and what type of treatment may be provided if it is likely that the person will imminently recover capacity
- (f) with respect to other such matters concerned with this Scheme as it thinks fit.”

3.119 The Commission is of the opinion that a multi-disciplinary approach best suits the formulation of the proposed Code of Practice on Advance Care Directives. The Commission accordingly recommends that a Code of Practice on Advance Care Directives should be prepared under the proposed statutory framework to provide guidance on the creation and execution of advance care directives. The Commission also recommends that the Code of Practice should be prepared by the proposed Office of Public Guardian and should be based on the recommendations of a multi-disciplinary Working Group established for this purpose by the Office of Public Guardian with input from the Health Service Executive, the Mental Health Commission and the Health Information and Quality Authority (HIQA) as envisaged under Head 39 of the *Scheme of a Mental Capacity Bill 2008*. The Commission considers that input could also be sought from, for example, the Medical Council, An Bord Altranais, patients’ groups, the Irish Hospice Foundation and HIQA.

3.120 *The Commission recommends that a Code of Practice on Advance Care Directives should be prepared under the proposed statutory framework to provide guidance on the creation and execution of advance care directives. The Commission also recommends that the Code of Practice should be prepared by the proposed Office of Public Guardian and should be based on the recommendations of a multi-disciplinary Working Group established for this purpose by the Office of Public Guardian with input sought from, for example, the Health Service Executive, the Medical Council, An Bord Altranais, patients’ groups, the Irish Hospice Foundation and HIQA.*

CHAPTER 4 CONSEQUENCES OF ESTABLISHING A STATUTORY FRAMEWORK

A Introduction

4.01 In this chapter the Commission discusses possible consequences arising out of advance care directives. In Part B the Commission discusses the implications for healthcare professionals who follow an advance care directive. Part C focuses on possible consequences for disregarding an advance care directive, including a discussion of a good faith defence and circumstances in which a healthcare professional has a conscientious objection to following an advance care directive. Finally in Part D the Commission makes recommendations on consequences for healthcare professionals who do not follow a valid and applicable advance care directive.

B Implications for following an advance care directive

4.02 In Chapter 1 the Commission recommended that the proposed legislative framework on advance care directives does not affect the current law of homicide under which euthanasia and assisted suicide are criminal offences. Thus, the Commission's proposed legislative framework, given these limits, does not legalise euthanasia or assisted suicide.¹ However, the Commission acknowledges that this does not prevent a person from refusing life-sustaining medical treatment in an advance care directive even if it results in death.

4.03 As the Commission has already discussed,² in 1986 Costello J, writing extra-judicially, discussed whether a doctor who turned off a life-support machine would be found guilty of homicide.³ Costello J stated that the switching off of a life-support machine is an act and the failure to switch back on the machine is an omission.⁴ It is this omission which would be the cause of death and Costello J stated that it is "a failure which can properly be regarded as an

¹ See paragraph 1.73-1.74.

² See paragraph 1.41.

³ Costello "The Terminally Ill-The Law's Concern" (1986) *Irish Jurist* 35.

⁴ *Ibid*, at 44.

omission.”⁵ The Supreme Court in *In Re a Ward of Court (No 2)*⁶ endorsed the approach taken by Costello J. Hamilton CJ stated that the case is “not about euthanasia, if by that is meant the taking of positive action to cause death”.⁷

4.04 Thus it would seem that a healthcare professional would not be liable for following an advance care directive which refuses life-sustaining medical treatment. The focus of Costello J’s 1986 lecture was on the terminally ill and thus does not discuss other types of medical treatment. However a healthcare professional may not administer any medical treatment without the consent of the person. Thus a healthcare professional may not administer medical treatment which is refused under an advance care directive. In light of this, the Commission recommends that, by way of confirming what appears to be the current law, the legislative scheme should provide that a healthcare professional will not be held liable for following a valid and applicable advance care directive.

4.05 *The Commission recommends that a healthcare professional will not be liable if they follow an advance care directive which they believe to be valid and applicable.*

C Disregarding an advance care directive

The Commission now turns to discuss the potential implications of disregarding an advance care directive. The Commission begins by examining current law in this respect and then discusses the potential effect of the proposed framework on advance care directives.

(1) Current law

(a) Necessity

4.06 As discussed already, a person must consent to medical treatment.⁸ However, the Commission has noted that in medical emergencies, such consent may not be necessary,⁹ On the basis of the doctrine of necessity, although the circumstances involved are limited.¹⁰ While there is some

⁵ Costello “The Terminally Ill-The Law’s Concern” (1986) *Irish Jurist* 35 at 44.

⁶ [1996] 2 IR 79.

⁷ *Ibid*, at 120.

⁸ See paragraph 1.86.

⁹ Law Reform Commission *Consultation Paper Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraph 5.08.

¹⁰ Charleton, McDermott and Bolger *Criminal Law* (Butterworths 1999), at paragraph 15.27.

confusion surrounding the application of the defence of necessity,¹¹ the Commission considers that the defence may apply in a life threatening situation where a person has a valid advance care directive. The defence may only apply in a medical emergency in which the person is unable to communicate with a medical professional.

4.07 The Commission has noted, in the context of persons who lack capacity to consent, that there may not be a consistent approach applied by medical professionals when assessing the scope of the defence of necessity. Some medical professionals err on the side of caution and carry out medical treatment where a person lacks capacity in life and death situations only. Other medical professionals rely on the doctrine of necessity and carry out all medical treatment on an adult who lacks capacity.¹² The Commission notes that, as the defence of necessity does not cover all situations to which an advance care directive may apply, the defence is clearly not applicable to all advance care directives.

(b) Assault

4.08 Section 2(1) of the *Non-Fatal Offences Against the Person Act 1997* states that:

“A person shall be guilty of the offence of assault who, without lawful excuse, intentionally or recklessly:

- (a) directly or indirectly applies to or force to or causes an impact to the body of another, or
- (b) causes another to believe on reasonable grounds that he or she is likely immediately to be subjected to such force or impact

without consent of the other.”

4.09 Thus medical treatment administered without consent could be considered to be assault, regardless of whether there is an advance care directive. Madden, however, is of the opinion that a doctor will presumably “have acted in good faith, and possibly in emergency circumstances when the imperative was to ‘act now and think later’, it is unlikely that such a prosecution would be brought.”¹³ The Commission agrees that this approach is likely to be applied and, indeed, considers it undesirable that a health care professional

¹¹ Law Reform Commission *Consultation Paper on Vulnerable Adults and the Law: Capacity* (LRC CP 37-2005), at paragraph 7.43.

¹² *Ibid*, at paragraph 5.10.

¹³ Madden *Medicine, Ethics and the Law* (Butterworths 1999), at paragraph 15.27.

who acted in good faith could be prosecuted for assault in situations where an advance care directive was involved.

(c) Civil liability

4.10 In the Consultation Paper the Commission noted that while a civil liability claim might be possible in the context of an advance care directive,¹⁴ it also noted that taking a claim against a doctor who did not follow an advance care directive is problematic as the person must prove that the doctor breached their duty of care. In the US decision *Allore v Fower Hospital*¹⁵ the court held that resuscitating the plaintiff's husband did not constitute a breach of the standard of care. A further problem is that a plaintiff must also prove that the health care professional caused harm; this may be problematic in the context of a person whose advance care directive involved a refusal of life-sustaining treatment, as the "harm" alleged would arguably involve a claim that the continuation of life should give rise to liability.

(2) Proposed statutory framework

(a) Good faith defence

4.11 The Commission has already noted that one must consent to medical treatment.¹⁶ The Commission, however, recognises that in a medical emergency where the patient is incapacitated, a patient will be unable to consent to medical treatment. The Commission has recommended establishing a central registry for advance care directives.¹⁷ This registry would be easily accessible for healthcare professionals to access an advance care directive in cases of medical emergency. The Commission recognises however, that in acute situations this will not always be possible.

4.12 As previously outlined, there is confusion and a lack of consistent approach in applying the defence of necessity in cases where consent cannot be obtained. This problem is not only confined to the emergency room but can include situations involving members of the emergency services and members of the public who voluntarily provide first aid or use an Automatic External Defibrillator (AED). The Commission is of the opinion that such people should not be at risk of liability, at least in the situations where they are not aware of an advance care directive. In such circumstances, the Commission considers that such a person should be regarded as having acted in good faith in attending to

¹⁴ Law Reform Commission *Consultation Paper Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraph 5.14-5.19

¹⁵ (1990) 497 US 261.

¹⁶ See paragraph 1.86.

¹⁷ See paragraph 3.96.

a person.¹⁸ The Commission recommends that while an advance care directive may exist, that person acted in good faith and thus should not be liable for what turn out in hindsight to be acting contrary to the advance care directive. However, to avail of this good faith defence the person must reasonably believe that an advance care directive does not exist.

4.13 *The Commission recommends that a good faith defence apply to persons who acted in good faith but contrary to an advance care directive which they were reasonably unaware of.*

(b) Conscientious objection

4.14 The Commission recognises that some doctors may have a moral and ethical objection to an advance care directive. The Irish Medical Council states that

“If a doctor has a conscientious objection to a course of action this should be explained and the names of other doctors made available to the patient.”¹⁹

4.15 In considering this point in the specific context of advance care directives, the Law Commission for England and Wales stated that in light of the patient’s right to refuse medical treatment, there should be no statutory provision that a doctor may refuse medical treatment if they have a conscientious objection.²⁰ The Code of Conduct for the English *Mental Capacity Act 2005* states that while a healthcare professional does not have to do something which goes against their beliefs, they cannot abandon a patient.²¹ The Code goes on to state that

“Healthcare professionals should make their views clear to the patient and the healthcare team as soon as someone raises the subject of withholding, stopping or providing life-sustaining treatment.”²²

“In cases where the patient now lacks capacity but has made a valid and applicable advance decision to refuse treatment which a doctor

¹⁸ See also the Commission’s *Report on Civil Liability of Good Samaritans and Volunteers* (LRC 93-2009).

¹⁹ Medical Council *A Guide to Ethical Behaviour and Conduct*, 6th edition, 2004, at paragraph 2.6.

²⁰ Law Commission for England and Wales *Report on Mental Incapacity* (No 231 1995), at paragraph 5.28.

²¹ Code of Conduct for *Mental Capacity Act 2005*, at paragraph 9.61.

²² *Ibid*, at paragraph 9.62.

or health professional cannot, for reasons of conscience, comply with, arrangements should be made for the management of the patient's care to be transferred to another healthcare professional. Where a transfer cannot be agreed, the Court of Protection can direct those responsible for the person's healthcare (for example, a Trust, doctor or other health professional) to make arrangements to take over responsibility for the person's healthcare."²³

4.16 The British Medical Association (BMA) notes that while healthcare professionals "are entitled to have their professional beliefs respected", they "cannot impose them on patients who do not share them."²⁴ The BMA recommends that

"In an emergency, if no other health professional is available, health staff with a conscientious objection should not act contrary to a known and valid advance refusal. It is unacceptable and lawful to force treatment upon a patient who has validly refused it in advance."²⁵

4.17 In Queensland, the *Powers of Attorney Act 1998* (Qld) provides that a health professional can refuse to follow an advance care directive if they reasonably believe that the advance care directive is contrary to good medical practice.²⁶ The provision does not state that a health professional must refuse to follow an advance care directive which is contrary to good medical practice, rather they can opt to follow such an advance care directive.²⁷

4.18 The Commission recognises the conflict which can occur between a health care professional who has a conscientious objection to an advance care directive. Nevertheless, due to the importance of ensuring that the proposed legislative framework can give real meaning to the autonomy, dignity and privacy of a person, the Commission has concluded that a health care professional cannot have a legal right to refuse to follow an advance care directive if they have a conscientious objection.

²³ Code of Conduct for *Mental Capacity Act 2005*, at paragraph 9.63.

²⁴ BMA "Advance Decisions and Proxy Decision-Making in Medical Treatment and Research" (2007), at 8.

²⁵ *Ibid.*

²⁶ Section 103(1) of the *Powers of Attorney Act 1996* (Qld).

²⁷ Wilmott, White and Howard "Refusing Advance Refusals: Advance Directives and Life-Sustaining Medical Treatment" (2006) 30 *Melbourne University Law Review* 211, at 235.

(3) Conclusion

4.19 The Commission notes that the current law contains provisions which may cover advance care directives and the failure of a health care professional to follow an advance care directive. As the Commission has outlined above, applying the current law to advance care directives is problematic. However the Commission is of the opinion that the proposed statutory framework should not affect any criminal or civil liability that may arise as a result of any current common law or statutory duty arising from carrying out or continuing the treatment specified in the advance care directive or from a failure to comply with the terms of the advance care directive.

4.20 *The Commission recommends that the proposed statutory framework should not affect any criminal or civil liability that may arise as a result of any current common law or statutory duty arising from carrying out or continuing the treatment specified in the advance care directive or from a failure to comply with the terms of the advance care directive.*

D Consequences for failing to follow an advance care directive

4.21 In the Consultation Paper the Commission noted that the purpose of an advance care directive is to ensure that a person retains autonomy over future medical treatments. Thus, if a healthcare professional refuses to follow an advance care directive, the autonomy of the person is infringed.²⁸ As the Irish Council for Bioethics noted:

“If the wishes of an individual as outlined in an advance care 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 a now incompetent adult to effectively oppose such decisions. 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, thus, violating their dignity and displaying a lack of respect for the wishes of the individual.”²⁹

4.22 Submissions received by the Commission during the consultation process on possible consequences were mixed. Particular apprehension was expressed at any consequences which might be perceived as punishing the medical profession for keeping a patient alive. Others felt that the failure to

²⁸ Law Reform Commission *Consultation Paper Bioethics: Advance Care Directives* (LRC CP 51-2008), at paragraph 5.61.

²⁹ Irish Council for Bioethics *Is it Time for Advanced Healthcare Directives?* (2007), at 14.

follow an advance care directive is an infringement of a person's constitutional rights, and that consequences must, therefore, follow. The Commission acknowledges that consequences for failing to follow an advance care directive are necessary to ensure that a patient's wishes are followed. The Commission however notes that any such consequences should not violate the duty of care a healthcare professional owes towards a patient and the oath that a doctor must take.

(1) Health Act 2004

4.23 Section 46(1) of the *Health Act 2004* states that

“Any person who is being or was provided with a health or personal social service by the [Health Service] Executive or by a service provider or who is seeking or has sought provision of such service may complain, in accordance with the procedures established under this Part, about any action of the Executive or a service provider that-

- (a) it is claimed, does not accord with fair and sound administrative practice, and
- (b) adversely affects or affected that person.”

It is notable that section 48(1)(b) of the 2004 Act states that a person may not complain about “a matter relating solely to the exercise of clinical judgement by a person acting on or behalf of the Executive or a service provider.” Thus it would appear that a complaint could not be made under the *Health Act 2004* if an advance care directive was not followed.

(2) Professional Misconduct

4.24 The Irish Medical Council guidance states that professional misconduct is

- “(a) conduct which doctors of good experience, competence and good repute consider disgraceful or dishonourable; and/or
- (b) Conduct connected with his or her profession in which the doctor concerned has seriously fallen short by omission or commission of the standards of conduct expected among doctors.”³⁰

4.25 Section 57 of the *Medical Practitioners Act 2007* states that any person (including the Council) may make a complaint to the Preliminary Proceedings Committee (PPC) on the grounds of professional misconduct. Upon receiving a report from the Fitness to Practice Committee (FCC), the

³⁰ Medical Council *A Guide to Ethical Behaviour and Conduct*, 6th edition, 2004, at paragraph 1.5.

Medical Council has the power to impose one or more of the following sanctions on a medical practitioner:

- (a) “an advice or admonishment, or a censure in writing;
- (b) a censure in writing and a fine not exceeding €5,000
- (c) the attachment of conditions to the practitioner’s registration, including restrictions on the practice of medicine that may be engaged in by the practitioner;
- (d) the transfer of the practitioner’s registration for a specified period;
- (e) the suspension of the practitioner’s registration for a specified period;
- (f) the cancellation of the practitioner’s registration;
- (g) a prohibition from applying for a specified period for the restoration of the practitioner’s registration.”³¹

4.26 If the Medical Council imposes a sanction more punitive than an advice, admonishment or censure, it must apply to the High Court to make that decision final.³²

4.27 The *Medical Practitioners Act 2007* does not define “professional misconduct.” Nevertheless guidance may be sought from *O’Laoire v Medical Council*.³³ Keane J set out four tests for establishing professional misconduct, the last of which may be appropriate for a patient wishing to complain against a physician who has disregarded their advance care directive:

“Conduct which could not properly be characterised as ‘infamous’ or ‘disgraceful’ and which does not involve any degree of moral turpitude, fraud or dishonesty may still constitute ‘professional misconduct’ if it is conduct connected with his profession in which the medical practitioner concerned has seriously fallen short, by omission or commission, of the standards of conduct expected among medical practitioners.”

This test is included in the most recent edition of the Medical Council’s Guide to Ethical Conduct and Behaviour (2004).

4.28 Under the *Nurses Act 1985*, the Fitness to Practice Committee composed of members of An Bord Altranais will determine whether a nurse is guilty of professional misconduct.³⁴ Upon the finding of professional misconduct,

³¹ Section 71 of the *Medical Practitioners Act 2007*.

³² Section 74 of the *Medical Practitioners Act 2007*.

³³ High Court (Keane J) 27 January 1995 109.

³⁴ Section 38(1) of the *Nurses Act 1985*.

the Board can erase the name of a nurse from the register permanently or for a specific period of time.³⁵ The Board may also opt to advise, admonish or censure a person in relation to their professional misconduct.³⁶ The Act, however, does provide a definition on professional misconduct. Similar powers are conferred on the Dental Council (under the *Dentists Act 1985*), the Pharmaceutical Society of Ireland (under the *Pharmacy Act 2007*) and the Health and Social Care Professionals Council (under the *Health and Social Care Professionals Act 2005*).

4.29 The Commission notes the conflict between ethical guidance and imposing sanctions on health care professionals for failing to follow an advance care directive. The Commission, however, considers that this must be balanced against the risk that an advance care directive could become a hollow document, repeatedly ignored if there are no consequences for failing to follow a valid and applicable advance care directive. The Commission thus is of the opinion that, while refusing to follow an advance care directive ought not to be a matter for criminal sanction, nevertheless the Commission is anxious that an advance care directive should be followed provided it is valid and applicable. In this respect, the Commission has concluded that the relevant statutory professional bodies, such as the Medical Council, An Bord Altranais, the Dental Council, the Pharmaceutical Society of Ireland and the Health and Social Care Professionals Council, are best suited to deal with the relevant healthcare professional using relevant statutory powers of investigation and inquiry into professional misconduct. The professional bodies will, the Commission considers, be best suited to consider whether disregarding an advance care directive in particular circumstances could amount to professional misconduct.

4.30 *The Commission recommends that the legislative framework for advance care directives should not preclude a relevant statutory health care professional body from inquiring into or investigating whether the failure of a health care professional to comply with an advance care directive constitutes professional misconduct.*

³⁵ Section 39(1) of the *Nurses Act 1985*.

³⁶ Section 41(1) of the *Nurses Act 1985*.

CHAPTER 5 SUMMARY OF RECOMMENDATIONS

The recommendations in this Report may be summarised as follows:

5.01 The Commission recommends that the term “advance care directive” be used in any legislative framework that deals with the advance expression of wishes of an individual in a health care or wider care setting. [Introduction, paragraph 7]

5.02 The Commission recommends that an appropriate legislative framework should be enacted for advance care directives, as part of the reform of the law on mental capacity in the Government’s *Scheme of a Mental Capacity Bill 2008*. [paragraph 1.63]

5.03 The Commission recommends that the proposed statutory framework on advance care directives should be facilitative in nature and be seen in the wider context of a process of health care planning by an individual, whether in a general health care setting or in the context of hospice care. [paragraph 1.71]

5.04 The Commission recommends that its proposed legislative framework for advance care directives does not alter or affect current law on homicide, under which euthanasia and assisted suicide are criminal offences. [paragraph 1.75]

5.05 The Commission recommends that the proposed legislative framework should apply to advance care directives that involve refusal of treatment, subject to certain conditions to be specified in the legislation. The Commission also recommends that an advance care directive should be defined as the expression of instructions or wishes by a person of 18 years with capacity to do so that, if (a) at a later time and in such circumstances as he or she may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him or her, and (b) at that time he or she lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued. [paragraph 1.82]

5.06 The Commission recommends that the proposed legislative framework should not apply to advance care directives involving mental health care. [paragraph 1.84]

5.07 The Commission recommends that informed decision making should be a principle that forms part of the legislative framework on advance care directives. The Commission also recommends that it should be made clear that a person is entitled to refuse medical treatment for reasons that appear not to be rational or based on sound medical principles and to refuse medical treatment for religious reasons. [paragraph 1.92]

5.08 The Commission recommends that the principles of autonomy, dignity and privacy of the individual should form part of the legislative framework for advance care directives. [paragraph 1.100]

5.09 The Commission recommends that if, following an appropriate process of consultation, a reasonable doubt exists as to the validity or meaning of an advance care directive, any such doubt must be resolved in favour of preserving life. [paragraph 1.106]

5.10 The Commission recommends that the existence of any advance care directive, including an advance care directive involving the appointment of a health care proxy, be brought to the attention of the Court when (as envisaged in the *Scheme of a Mental Capacity Bill 2008*) it considers the appointment of a personal guardian. The Commission also recommends that the powers of a personal guardian should not include any powers which would conflict with any provision in an advance care directive. [paragraph 2.07]

5.11 The Commission recommends that the Government's *Scheme of a Mental Capacity Bill 2008* be extended to provide that a person may appoint an attorney under an enduring power of attorney (EPA) to make decisions regarding life-sustaining treatment, organ donation and non-therapeutic sterilisation, provided that these are expressly provided for in the EPA. [paragraph 2.22]

5.12 The Commission recommends that, in general, in the event of a conflict between the terms of an enduring power of attorney (EPA) executed under the *Powers of Attorney Act 1996* and an advance care directive, the EPA should take priority over an advance care directive. The Commission also recommends that, where it appears that a conflict arises between the terms of an EPA and an advance care directive, there should initially be an attempt to resolve any apparent conflict informally, involving the donee of the enduring power of attorney and the relevant health care professional, and, where applicable, the health care proxy. The Commission also recommends that, in the absence of agreement between the parties, the matter should be referred to the High Court for resolution. [paragraph 2.24]

5.13 The Commission recommends that a health care proxy may be appointed under an advance care directive [paragraph 2.31]

5.14 The Commission recommends that the legislative framework for advance care directives contains a very wide definition of healthcare professional, which includes those involved in the medical, spiritual, emotional and psychological care of a person. [paragraph 3.05]

5.15 The Commission recommends that basic care cannot be refused under an advance care directive. The Commission recommends that basic care should be defined to include, but is not limited to, warmth, shelter, oral nutrition and hydration and hygiene measures. The Commission also recommends that the proposed Code of Practice on Advance Care Directives should contain detailed guidance for health care professionals on what constitutes basic care. [paragraph 3.09]

5.16 The Commission recommends that palliative care should be regarded as part of basic care. The Commission also recommends that the proposed Code of Practice on Advance Care Directives should include detailed guidance on what constitutes palliative care. [paragraph 3.13]

5.17 The Commission recommends that an advance care directive may include a refusal of life-sustaining treatment, that is, treatment which is intended to sustain or prolong life and that supplants or maintains the operation of vital bodily functions that are incapable of independent operation. The Commission also recommends that the proposed Code of Practice on Advance Care Directives should include detailed guidance on the types of treatment that come within the definition of life-sustaining treatment. [paragraph 3.18]

5.18 The Commission recommends that the proposed Code of Practice on Advance Care Directives should provide guidance on the circumstances in which artificial nutrition and hydration (ANH) may be considered to be basic care and, as the case may be, artificial life-sustaining treatment. In deciding whether ANH is basic care or artificial life-sustaining treatment, the decision should be based on the health care professional's medical and professional judgment only. [paragraph 3.27]

5.19 The Commission recommends that the Code of Practice on Advance Care Directives should contain guidelines on the process of putting in place a DNR order. The Commission also recommends that the guidelines should provide that before a DNR order is made there is a consultative process, that this is documented on the patient's chart and that it is made by the most senior available member of the healthcare team. [paragraph 3.32]

5.20 The Commission recommends that, subject to the situation of life-sustaining treatment, an unwritten advance care directive is enforceable under the proposed statutory framework. The Commission also recommends that the proposed Code of Practice on Advance Care Directives should include guidance on the types of circumstances in which an unwritten advance care

directive would be likely to be enforceable under the proposed statutory framework. [paragraph 3.41]

5.21 The Commission recommends that an advance care directive that involves a refusal of life-sustaining medical treatment must be in writing (and that “writing” includes both manual and automated record-keeping processes). [paragraph 3.48]

5.22 The Commission recommends that, where an individual chooses to prepare a written advance care directive (or is required to do so because it involves life-sustaining treatment), it need not be in a prescribed form but must contain certain core information, such as: name of person making the advance care directive, date of birth, address, health care proxy (if any), and name and address of general practitioner or other health care professional. The Commission also recommends that the proposed Code of Practice on Advance Care Directives should contain guidance on what should be included in the advance care directive. [paragraph 3.49]

5.23 The Commission recommends that a refusal of treatment recorded on a person’s medical charts or notes may be deemed to be a written advance care directive and that a clear written statement in the form of for example, a ‘no blood’ card is deemed to be an advance care directive. [paragraph 3.50]

5.24 The Commission recommends that an advance care directive which involves the refusal of life-sustaining treatment must be witnessed by at least one person. [paragraph 3.59]

5.25 The Commission recommends that, for the time being, the legislative framework should apply only to those aged 18 years or more. [paragraph 3.61]

5.26 The Commission recommends that the rebuttable presumption of mental capacity should expressly apply to the maker of an advance care directive. The Commission also recommends that the proposed Code of Practice on Advance Care Directives should include guidance on the assessment of the capacity of an individual in this context. [paragraph 3.65]

5.27 The Commission recommends that makers of advance care directives should be encouraged to consult with a health care professional. In the case of advance care directives refusing life-sustaining medical treatment, the Commission recommends that the decision must be an informed decision. [paragraph 3.70]

5.28 The Commission recommends that an advance care directive will be valid where

- The author of the advance care directive had capacity at the time of its making

- The making of the advance care directive was the voluntary act of the author, and
- The maker has not communicated alteration or withdrawal of the refusal of treatment contained in the advance care directive. [paragraph 3.77]

5.29 The Commission recommends that an advance care directive will be applicable if

- The treatment is the treatment specified in the advance care directive
- All the circumstances outlined are present
- While competent, the author of the advance care directive said or did nothing which puts reasonable doubt in the mind of the health care professional that the author had changed their mind but did not have the opportunity to revoke the advance care directive.
- If the advance care directive is ambiguous, there will be a presumption in favour of the preservation of life. [paragraph 3.86]

5.30 The Commission recommends that the High Court be empowered to determine whether an advance care directive exists, whether it is valid and whether it is applicable to the relevant treatment under consideration. [paragraph 3.87]

5.31 The Commission recommends that a competent person can verbally revoke their advance care directive regardless of whether there is a verbal or written advance care directive. [paragraph 3.89]

5.32 The Commission recommends that the proposed Code of Practice on Advance Care Directives should recommend that advance care directives are reviewed regularly, but that there should be no specific time limit put on the validity of advance care directives. The Commission also recommends, however, that a health care professional may take into consideration the lapse of time between the making of an advance care directive and its activation. [paragraph 3.93]

5.33 The Commission recommends the establishment of a register of advance care directives, especially those which must be in writing under the proposed statutory framework, and that suitable guidance on its development could be given in the proposed Code of Practice on Advance Care Directives. [paragraph 3.96]

5.34 The Commission recommends that the maker of an advance care directive can confer a limited power on the maker of an advance care directive which can be

- Ensuring that the wishes of the maker of the advance care directive are carried out
- Consultation with a health care professional if there is ambiguity in the advance care directive [paragraph 3.104]

5.35 The Commission recommends that the maker of an advance care directive can confer a general power to refuse health care decisions on a health care proxy, except life-sustaining treatment.[paragraph 3.105]

5.36 The Commission recommends a health care proxy will not have the power to refuse life-sustaining treatment unless the advance care directive explicitly states that the health care proxy has such a power.[paragraph 3.106]

5.37 The Commission recommends the proposed Code of Practice on Advance Care Directives should include guidance on resolving any disputes between a healthcare proxy and a health care professional.[paragraph 3.107]

5.38 The Commission recommends that an advance care directive that includes the appointment of a proxy may be unwritten or written. [paragraph 3.111]

5.39 The Commission recommends that the maker of an advance care directive must explicitly state in a written advance care directive that they are granting the health care proxy the power to refuse artificial life-sustaining treatment and outline the scope of that power. [paragraph 3.112]

5.40 The Commission recommends that a written advance care directive appointing a proxy must contain

- Name of the proxy
- Address of the proxy [paragraph 3.113]

5.41 The Commission recommends that the maker of the advance care directive and the proxy should be encouraged to discuss the advance care directive. [paragraph 3.115]

5.42 The Commission recommends that a Code of Practice on Advance Care Directives should be prepared under the proposed statutory framework to provide guidance on the creation and execution of advance care directives. The Commission also recommends that the Code of Practice should be prepared by the proposed Office of Public Guardian and should be based on the recommendations of a multi-disciplinary Working Group established for this purpose by the Office of Public Guardian with input sought from, for example, the Health Service Executive, the Medical Council, An Bord Altranais, patients' groups, the Irish Hospice Foundation and HIQA. [paragraph 3.120]

5.43 The Commission recommends that a healthcare professional will not be liable if they follow an advance care directive which they believe to be valid and applicable. [paragraph 4.05]

5.44 The Commission recommends that a good faith defence apply to persons who acted in good faith but contrary to an advance care directive which they were reasonably unaware of. [paragraph 4.13]

5.45 The Commission recommends that the proposed statutory framework should not affect any criminal or civil liability that may arise as a result of any current common law or statutory duty arising from carrying out or continuing the treatment specified in the advance care directive or from a failure to comply with the terms of the advance care directive. [paragraph 4.20]

5.46 The Commission recommends that the legislative framework for advance care directives should not preclude a relevant statutory health care professional body from inquiring into or investigating whether the failure of a health care professional to comply with an advance care directive constitutes professional misconduct. [paragraph 4.30].

APPENDIX DRAFT MENTAL CAPACITY (ADVANCE CARE DIRECTIVES) BILL 2009¹

¹ In paragraph 1.63, the Commission recommends that the legislative framework for advance care directives be placed within the wider context of reform of the law on mental capacity in the Government's *Scheme of a Mental Capacity Bill 2008*. For this reason, this draft Bill has been prepared on the basis that it could constitute an additional Part of the Government's 2008 Scheme of a Bill.

DRAFT MENTAL CAPACITY (ADVANCE CARE DIRECTIVES) BILL 2009

ARRANGEMENT OF SECTIONS

1. Short title and commencement²
2. Interpretation
3. Purpose and guiding principles
4. Making an advance care directive, general scope and withdrawal
5. Conditions and requirements for advance care directives
6. Health care proxy
7. Code of Practice on Advance Care Directives
8. Powers of Court
9. Criminal and civil liability
10. Enduring powers of attorney and advance care directives

² Section 1 would become redundant if this draft Bill is incorporated into the Government's *Scheme of a Mental Capacity Bill 2008*.

ACTS REFERRED TO

Mental Health Act 2001

2001, No.25

Powers of Attorney Act 1996

1996, No.12

DRAFT MENTAL CAPACITY (ADVANCE CARE DIRECTIVES) BILL 2009

BILL

entitled

AN ACT TO PROVIDE FOR THE MAKING OF ADVANCE CARE DIRECTIVES³

BE IT ENACTED BY THE OIREACHTAS AS FOLLOWS:

Short title and commencement⁴

1.—(1) This Act may be cited as the Mental Capacity (Advance Care Directives) Act 2009.

(2) This Act comes into operation on such day or days as the Minister for Justice, Equality and Law Reform may appoint by order or orders either generally or with reference to any particular purpose or provision, and different days may be so appointed for different purposes or provisions.

Interpretation

2. — (1) In [this Part],⁵ unless the context otherwise requires—

“applicable” has the meaning assigned by *section 5*,

³ This could be added to the Long Title of the Government’s *Mental Capacity Bill*, which would be based on the Government’s *Scheme of a Mental Capacity Bill 2008*.

⁴ Section 1 would become redundant if this draft Bill is incorporated into the Government’s *Scheme of a Mental Capacity Bill 2008*.

⁵ The use of the words “this Part” would be correct if this draft Bill is incorporated into the Government’s *Scheme of a Mental Capacity Bill 2008*.

“basic care” includes, but is not limited to, warmth, shelter, oral nutrition and hydration and hygiene measures, and palliative care;

“advance care directive” means a valid and applicable advance expression of instructions or wishes, made by a person with capacity in accordance with *sections 4 and 5*, concerning health care issues that may arise in the event of the person’s incapacity;

“health care” excludes mental health care and mental health services within the meaning of the Mental Health Act 2001;

“health care professional” means a person involved in the medical, spiritual, emotional or psychological care of a person;

“relevant professional body” includes An Bord Altranais, the Dental Council, the Medical Council, the Pharmaceutical Society of Ireland, and the Health and Social Care Professionals Council,

“specified treatment” includes life-sustaining treatment, that is, treatment which is intended to sustain or prolong life and that supplants or maintains the operation of vital bodily functions that are incapable of independent operation,

“valid” has the meaning assigned by *section 5*,

“writing” includes both manual and automated record-keeping processes.

Explanatory Note

This section implements the recommendations in: paragraph 1.82 (general definition of “advance care directive” which draws on the Council of Europe’s 2009 *Draft Recommendation on Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity*); paragraph 1.84 (exclusion of mental health care); paragraph 3.05 (definition of “healthcare professional”); paragraphs 3.09 and 3.13 (definition of “basic care”); paragraph 3.18 (inclusion of life-sustaining treatment as specified treatment); and paragraph 3.48 (definition of “writing”).

Purpose and guiding principles

3. — Every person concerned in the application of [this Part]⁶ shall, in addition to having regard to the general guiding principles for this Act,⁷ have regard to the following—

(a) that the purpose of [this Part]⁸ is to facilitate the use of advance care directives in the wider setting of a process of health care planning by an individual,

(b) that an advance care directive should be made on the basis of informed decision-making,

(c) that a person is entitled to refuse medical treatment for reasons that appear not to be rational or to be based on sound medical principles, and

(d) that a person is entitled to refuse medical treatment for religious reasons.

Explanatory Note

This section implements the recommendation in paragraph 1.71 concerning the facilitative purpose of the legislative framework. It also implements the recommendations on guiding principles in paragraphs 1.92 and 1.100.

Making an advance care directive, general scope and withdrawal

4.—(1) Any person who has reached the age of 18 and who has capacity within the meaning of this Act⁹ may make an advance care directive.

(2) An advance care directive need not be made in writing and may be expressed in plain, non-technical, language.

⁶ The use of the words “this Part” would be correct if this draft Bill is incorporated into the Government’s *Scheme of a Mental Capacity Bill 2008*.

⁷ This refers to the guiding principles in Head 1 of the Government’s *Scheme of a Mental Capacity Bill 2008*.

⁸ The use of the words “this Part” would be correct if this draft Bill is incorporated into the Government’s *Scheme of a Mental Capacity Bill 2008*.

⁹ The reference to “capacity as defined in this Act” is to the definition of “capacity” in Head 2 of the Government’s *Scheme of a Mental Capacity Bill 2008*.

(3) The scope of an advance care directive shall extend to the expression of instructions or wishes by the person that if—

(a) at a later time and in such circumstances as he or she may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him or her, and

(b) at that time he or she lacks capacity to consent to the carrying out or continuation of the treatment,
the specified treatment is not to be carried out or continued.

(4) The person may withdraw or alter an advance care directive, whether in whole or in part, at any time when he or she has capacity to do so within the meaning of this Act.¹⁰

(5) The provisions in this section are subject to the relevant conditions and requirements in *section 5*.

Explanatory Note

Subsection (1) implements the recommendations in paragraphs 1.63, 3.61 and 3.65 that the legislative framework for advance care directives forms part of the general reform of mental capacity law in the Government's *Scheme of a Mental Capacity Bill 2008*; (including a presumption of capacity); and that it be limited, for the time being, to persons who are at least 18 years of age. *Subsection (2)* implements the recommendation in paragraph 3.41 that an advance care directive need not be made in writing. This is consistent with the Council of Europe's 2009 *Draft Recommendation on Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity*. *Subsection (3)* implements the recommendation in paragraph 1.82 that the legislative framework applies to refusals of treatment. *Subsection (4)* implements the recommendation in paragraph 3.89 on the withdrawal or alteration of an advance care directive.

Conditions and requirements for advance care directives

5.— (1) For the purposes of [this Part]¹¹ an advance care directive is valid if—

¹⁰ The reference to “capacity as defined in this Act” is to the definition of “capacity” in Head 2 of the Government's *Scheme of a Mental Capacity Bill 2008*.

¹¹ The use of the words “this Part” would be correct if this draft Bill is incorporated into the Government's *Scheme of a Mental Capacity Bill 2008*.

(a) the person who made the advance care directive had capacity at the time of its making,

(b) the making of the advance care directive was the voluntary and informed act of the person, and

(c) the person who made the advance care directive has not communicated an alteration or withdrawal of the refusal of treatment contained in the advance care directive.

(2) For the purposes of [this Part]¹² an advance care directive is applicable if—

(a) the treatment is the treatment specified in the advance care directive,

(b) all the circumstances outlined are present, and

(c) the person who made the advance care directive did not say or do anything which puts reasonable doubt in the mind of a health care professional that the person had changed his or her mind but did not have the opportunity to alter or withdraw the advance care directive.

(3) Without prejudice to any other provision of [this Part]¹³ an advance care directive that involves a refusal of basic care is not valid.

(4) (a) Without prejudice to *section 4(2)*, an advance care directive that involves a refusal of life-sustaining treatment shall be in writing.

(b) A written advance care directive that involves a refusal of life-sustaining treatment need not be in a prescribed form but shall contain at least the following information—

(i) the name, date of birth and address of the person making the advance care directive,

¹² The use of the words “this Part” would be correct if this draft Bill is incorporated into the Government’s *Scheme of a Mental Capacity Bill 2008*.

¹³ The use of the words “this Part” would be correct if this draft Bill is incorporated into the Government’s *Scheme of a Mental Capacity Bill 2008*.

(ii) the name and address of that person's general practitioner or other health care professional, and

(iii) the name and address of the health care proxy (if any).

(c) A written advance care directive that involves a refusal of life-sustaining treatment person shall be witnessed by at least one person.

(5) A refusal of treatment (other than one that involves a refusal of life-sustaining treatment) constitutes a valid advance care directive where —

(a) it is recorded on a person's medical charts or notes, or

(b) it is contained in a clear written statement such as the card commonly known as a "no blood" card.

(6) Where, following an appropriate process of consultation, any term of an advance care directive is ambiguous, any such doubt shall be resolved in favour of the preservation of life.

(7) A person may verbally revoke an advance care directive at any time whether the advance care directive was made in written or unwritten form.

(8) The length of time between the making of an advance care directive and its activation does not affect its validity or applicability, but a health care professional may have regard to the length of time in determining its applicability to the specified treatment.

Explanatory Note

Subsection (1) implements the recommendations in: paragraph 3.77 concerning the general conditions for the validity of an advance care directive; and in paragraph 3.70 concerning informed decision-making. *Subsection (2)* implements the recommendations in paragraph 3.86 concerning the general conditions for the applicability of an advance care directive. *Subsection (3)* implements the recommendation in paragraph 3.09 that an advance care directive shall not involve the refusal of basic care. *Subsection (4)(a)* implements the recommendation in paragraph 3.48 that an advance care directive involving a refusal of life-sustaining medical treatment must be in writing. *Subsection (4)(b)* implements the recommendation in paragraph 3.49 that such a written advance care directive need not be in a prescribed form but must contain certain specified information at least. *Subsection (4)(c)* implements the recommendation in paragraph 3.59 requiring that any advance care directive involving the refusal of life-sustaining treatment must be

witnessed. *Subsection (5)* implements the recommendation in paragraph 3.50 concerning the validity of advance care directives recorded on medical records or in clear written forms such as “no blood” cards. *Subsection (6)* implements the recommendations in paragraphs 1.106 and 3.86 concerning a presumption in favour of preserving life in the event of any ambiguity in an advance care directive. *Subsection (7)* implements the recommendation in paragraph 3.89 that an advance care directive, whether unwritten or written, may be revoked verbally. This is consistent with the Council of Europe’s 2009 *Draft Recommendation on Principles Concerning Continuing Powers of Attorney and Advance Directives for Incapacity*. *Subsection (8)* implements the recommendation in paragraph 3.93 concerning lapse of time between making an advance care directive and its activation.

Health care proxy

6.— (1) A health care proxy may be appointed under an advance care directive.

(2) The maker of an advance care directive may confer on a health care proxy powers limited to —

(a) ensuring that the terms of the advance care directive are carried out, and

(b) consulting with a health care professional in the event that there is ambiguity in any provision of the advance care directive.

(3) (a) The maker of an advance care directive may confer on a health care proxy a general power to refuse health care treatment, with the exception of refusal of life-sustaining treatment.

(b) (i) The maker of an advance care directive may confer on a health care proxy a specific power to refuse health care treatment, including refusal of life-sustaining treatment.

(ii) Where the maker of an advance care directive confers on a health care proxy a specific power to refuse life-sustaining treatment, the advance care directive shall be witnessed.

(4) (a) An advance care directive that includes the appointment of a health care proxy need not be in writing.

(b) Without prejudice to *section 5(4)(b)(iii)*, any written advance care directive appointing a health care proxy shall contain the name and address of the health care proxy.

(c) The maker of the advance care directive should, but need not, discuss the terms of an advance care directive with the health care proxy.

Explanatory Note

Subsection (1) implements the recommendation in paragraph 2.31 that a health care proxy may be appointed under an advance care directive. *Subsection (2)* implements the recommendation in paragraph 3.104 concerning the conferral of limited powers on a health care proxy. *Subsection (3)(a)* implements the recommendation in paragraph 3.105 concerning the conferral of a general power on a health care proxy, which may not include refusal of life-sustaining treatment. *Subsection (3)(b)(i)* implements the recommendation in paragraph 3.106 concerning the conferral of a specific power on a health care proxy, which may include refusal of life-sustaining treatment. *Subsection (3)(b)(i)* confirms, in accordance with the recommendation in paragraph 3.48, that such an advance care directive must be witnessed. *Subsection (4)(a)* implements the recommendation in paragraph 3.111 that a health care proxy need not be appointed in writing. *Subsection (4)(b)* implements the recommendation in paragraph 3.113 concerning the details to be included where the maker chooses to appoint a health care proxy in writing. *Subsection (4)(c)* implements the recommendation in paragraph 3.115 concerning discussions between the maker of the advance care directive and the health care proxy.

Code of Practice on Advance Care Directives

7.— (1) The Office of Public Guardian¹⁴ shall publish a Code of Practice on Advance Care Directives, based on the recommendations of a Working Group established by the Office of Public Guardian for this purpose, which shall provide practical guidance for the purposes of compliance with the provisions of [this Part].¹⁵

¹⁴ This is a reference to the Office of Public Guardian envisaged in Head 28 of the Government's *Scheme of a Mental Capacity Bill 2008*.

¹⁵ The use of the words "this Part" would be correct if this draft Bill is incorporated into the Government's *Scheme of a Mental Capacity Bill 2008*.

(2) Without prejudice to the generality of *subsection (1)*, the Code of Practice on Advance Care Directives shall include guidance on the following matters —

- (a) treatment that constitutes basic care,
- (b) treatment that constitutes palliative care,
- (c) treatment that constitutes life-sustaining treatment,
- (d) the circumstances in which artificial nutrition and hydration may be considered to be basic care and, as the case may be, life-sustaining treatment,
- (e) the process of putting in place a Do Not Resuscitate Order, including the need for a prior consultative process, that this is documented on a person's medical chart and that it is made by the most senior available member of the healthcare team,
- (f) the circumstances in which an unwritten advance care directive is likely to be valid and applicable under [this Part],
- (g) specified information (in addition to mandatory information required by [this Part]) that could be included in a written advance care directive,
- (h) the approach to assessment of the capacity of the person making an advance care directive,
- (i) suggested periods within which an advance care directive ought to be reviewed and the factors to be taken into account by health care professionals where it has not been reviewed regularly,
- (j) the process for establishing a register of advance care directives, and
- (k) the process for resolving any disputes between a healthcare proxy and a health care professional.

Explanatory Note

Subsection (1) implements the recommendation in paragraph 3.120 that a Code of Practice on Advance Care Directives should be prepared by the Office of Public Guardian. *Subsection (2)* implements the recommendations concerning the detailed contents of the Code of Practice in: paragraph 3.09 (basic care),

paragraph 3.13 (palliative care), paragraph 3.18 (life-sustaining treatment), paragraph 3.27 (circumstances in which ANH may be considered basic care and, as the case may be, life-sustaining treatment), paragraph 3.32 (DNR procedure), paragraph 3.41 (unwritten advance care directives), paragraph 3.49 (information to be included in a written advance care directive), paragraph 3.65 (assessment of capacity), paragraph 3.93 (suggested review periods for advance care directives), paragraph 3.96 (register of advance care directives) and paragraph 3.107 (disputes between a healthcare proxy and a health care professional).

Powers of Court

8.— On an application by any interested party under [this Part],¹⁶ the Court¹⁷ may make a declaration as to whether an advance care directive —

(a) exists,

(b) is valid, or

(c) is applicable to a specific treatment.

Explanatory Note

This section implements the recommendations in paragraph 3.87 concerning the powers of the Court of Care and Protection envisaged by the Government's *Scheme of a Mental Capacity Bill 2008*.

¹⁶ The use of the words “this Part” would be correct if this draft Bill is incorporated into the Government's *Scheme of a Mental Capacity Bill 2008*.

¹⁷ This is a reference to the Court of Care and Protection envisaged in the Government's *Scheme of a Mental Capacity Bill 2008*.

Civil and criminal liability

9.— (1) Nothing in [this Part]¹⁸ shall be construed as imposing any criminal liability or civil liability arising from —

(a) carrying out or continuing the treatment specified in an advance care directive, or

(b) failure to comply with the terms of an advance care directive.

(2) Nothing in this Act shall be construed as affecting any civil liability that may otherwise arise as a result of any common law duty or statutory duty (excluding the provisions of this Act) arising from —

(a) carrying out or continuing the treatment specified in an advance care directive, or

(b) failure to comply with the terms of an advance care directive.

(3) Nothing in this Act shall be construed as altering or affecting any criminal liability that may otherwise arise, whether at common law or by virtue of statute law (excluding the provisions of this Act), arising from —

(a) carrying out or continuing the treatment specified in an advance care directive, or

(b) failure to comply with the terms of an advance care directive.

(4) Nothing in this Act shall be construed as preventing a relevant professional body from carrying out an investigation or inquiry into the conduct of a health care professional who fails to comply with an advance care directive.

(5) In any proceedings, whether civil or criminal, or in any investigation or inquiry, it is a full defence that the health care professional, acting in good faith, was unaware of the existence of the advance care directive at the time the specified treatment was carried out or continued.

Explanatory Note

Subsection (1) implements the recommendation in paragraph 4.05 that the legislative framework does not give rise to any civil liability or criminal liability.

¹⁸ The use of the words “this Part” would be correct if this draft Bill is incorporated into the Government’s *Scheme of a Mental Capacity Bill 2008*.

Subsection (2) implements the recommendation in paragraph 4.20 that the legislative framework does not affect any civil liability that might otherwise arise. *Subsection (3)* implements the recommendation in paragraph 1.75 that the legislative framework does not alter or affect any criminal liability that might otherwise arise. *Subsection (4)* implements the recommendation in paragraph 4.30 that the legislative scheme does not prevent a relevant professional body from investigating or inquiring into a health care professional for failing to comply with an advance care directive. *Subsection (5)* implements the recommendation in paragraph 4.13 that it will be a full defence in any proceedings, investigation or inquiry that the health care professional, acting in good faith, was unaware of the existence of the advance care directive at the time.

Enduring powers of attorney and advance care directives

10.— (1) Subject to *subsections (2) and (3)*, in the event of a conflict between the terms of an enduring power of attorney executed under the Powers of Attorney Act 1996 and an advance care directive made under [this Part],¹⁹ effect shall be given to the enduring power of attorney.

(2) Where it appears that a conflict arises between the terms of an enduring power of attorney executed under the Powers of Attorney Act 1996 and an advance care directive made under [this Part], the donee of the enduring power of attorney and the relevant health care professional (and, where applicable, the health care proxy) shall endeavour to resolve any apparent conflict.

(3) Where the parties referred to in *subsection (2)* are unable to resolve any such apparent conflict, the matter shall be referred to the Court,²⁰ which may make a declaration as to the whether a conflict arises and, if such conflict arises, as to whether effect shall be given to the terms of the enduring power of attorney or to the terms of the advance care directive.

(4) An enduring power of attorney executed under the Powers of Attorney Act 1996 may confer on the donee the power to make decisions regarding life-sustaining treatment, organ donation and non-therapeutic sterilisation.

¹⁹ The use of the words “this Part” would be correct if this draft Bill is incorporated into the Government’s *Scheme of a Mental Capacity Bill 2008*.

²⁰ This is a reference to the Court of Care and Protection envisaged in the Government’s *Scheme of a Mental Capacity Bill 2008*.

Explanatory Note

Subsections (1) to (3) implement the recommendations in paragraph 2.24 that: (a) in general an enduring power of attorney executed under the *Powers of Attorney Act 1996* takes priority over an advance care directive; (b) any apparent conflict should initially be resolved informally; and (c) where the conflict cannot be resolved informally, the High Court has jurisdiction to deal with the matter. *Subsection (4)* implements the recommendation in paragraph 2.22 that an enduring power of attorney executed under the *Powers of Attorney Act 1996* may confer on the donee the power to make decisions regarding life-sustaining treatment, organ donation and non-therapeutic sterilisation; this recommendation could also be implemented by an amendment to Head 48(3)(ii) of the Government's *Scheme of a Mental Capacity Bill 2008*.



The Law Reform Commission is an independent statutory body established by the *Law Reform Commission Act 1975*. The Commission's principal role is to keep the law under review and to make proposals for reform, in particular by recommending the enactment of legislation to clarify and modernise the law.

This role is carried out primarily under a Programme of Law Reform. The Commission's *Third Programme of Law Reform 2008-2014* was prepared and approved under the 1975 Act following broad consultation and discussion. The Commission also works on specific matters referred to it by the Attorney General under the 1975 Act. Since 2006, the Commission's role also includes two other areas of activity, Statute Law Restatement and the Legislation Directory. Statute Law Restatement involves incorporating all amendments to an Act into a single text, making legislation more accessible. The Legislation Directory (previously called the Chronological Tables of the Statutes) is a searchable guide of legislative changes.

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