



LAW REFORM
COMMISSION/COIMISIÚN UM
ATHCHÓIRIÚ AN DLÍ

CONSULTATION PAPER

BIOETHICS: ADVANCE CARE DIRECTIVES

[LRC CP 51 – 2008]



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However, full responsibility for this publication lies with the Commission.

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Age of Legal Capacity (Scotland) Act 1991	1991, c.50	Scot
Age of Majority Act 1985	No. 2 of 1985	Irl
Consent to Medical Treatment and Palliative Care Act 1995 (SA)	1995	Aus
Control of Clinical Trials Act 1987	No. 28 of 1987	Irl
Criminal Justice (Theft and Fraud Offences) Act 2001	No.50 of 2001	Irl
Family Law Reform Act 1969	1969, c.46	Eng
Guardianship and Administration Act 2000 (Qld)	2000	Aus
Health Act 1953	No. 26 of 1953	Irl
Health Act 2005	No. 546 of 2005	Den
Health Care Consent Act SO 1996	1996, c. 2	Can
Health Care Directives Act CCSM 1993	1993, c. H-27	Can
Healthcare (Consent) and Care Facility (Admission) Act RSBC 1996	1996, c. 181	Can
Medical Practitioners Act 2007	No. 25 of 2007	Irl
Medical Treatment (Health Directions) Act 2006	2006	Aus
Medical Treatment Act 1988 (Vic)	1988	Aus
Medical Treatment Act 1994 (ACT)	1994	Aus
Mental Capacity Act 2005	2005, c.9	Eng
Mental Health (Care and Treatment) (Scotland) Act 2003	2003 asp 13	Scot
Mental Health Act 2007	2007, c. 12	Eng
Natural Death Act 1988 (NT)	1988	Aus
Non-Fatal Offences Against the Person Act 1997	No. 26 of 1997	Irl
Powers of Attorney Act 1996	No. 12 of 1996	Irl
Powers of Attorney Act 1998 (Qld)	1998	Aus
Succession Act 1965	No. 27 of 1965	Irl

The Health Care Directives and Substitute Health Care Decision Makers Act, SS 1997	1997, c. H-001	Can
Theft Act 1968	1968, c. 60	Eng

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Airedale NHS Trust v Bland	[1993] 1 All ER 821	Eng
Allore v Flower Hospital	(1997) 699 NE 2d 560	US
Anderson v St Francis-St George Hospital	(1996) 671 NE 225	US
B v An NHS Trust	[2002] EWHC 429	Eng
Bowman v Davis	(1976) 356 NE2d 496	US
Bruni v Tatsumi	(1976) 346 NE 2d 673	US
Cruzan v Director Missouri Department of Health	(1990) 497 US 261	US
Daniels v Heskin	[1954] IR 73	Irl
Denmark, Norway, Sweden and the Netherlands v Greece	(1969) 12 YB 1	ECtHR
Dunne v National Maternity Hospital	[1989] IR 91	Irl
Educational Company of Ireland v Fitzpatrick (No 1)	[1961] IR 323	Irl
Estate of Leach v Shapiro	(1984) 1052 NE 2d 1047	US
Fitzpatrick v FK	[2008] IEHC104	Irl
Gillick v West Norfolk and Wisbech AHA	[1986] AC 112	Eng
HE v A Hospital NHS Trust	[2003] EWHC 1017, [2003] 2 FLR 408	Eng
Herczegfalvy v Austria	(1992) Series A No 244	ECtHR
Hoffmann v Austria	(1993) Series A No 106	ECtHR
In re a Ward of Court (withholding medical treatment) (No 2)	[1996] 2 IR 79	Irl
Johnson v University Hospital of Cleveland	(1989) 540 NE2d 1370	US
Kearney v The Minister for Justice	[1986] IR 116	Irl
Kennedy v Ireland	[1987] IR 587	Irl

Leame v Bray	(1803) 3 East 593	Eng
Lochner v New York	(1905) N 198 US 43	US
Lovett v Gogan	[1995] 1 ILRM 12	Irl
Malette v Schulman	(1987) 67 DLR (4th) 321	Can
McHugh v Commissioner of An Garda Siochana	[1986] IR 228	Irl
McKay v Essex Area Health Authority	[1982] 2 All ER 771	Eng
Meskill v CIE	[1973] IR 121	Irl
Ms B v A NHS Hospital Trust	[2002] EWHC 429	Eng
N v Health Service Executive	[2006] 4 IR 374	Irl
NHS Trust A v M; NHS Trust B v H	[2001] 1 All ER 801	Eng
NHS Trust v T (adult patient: refusal of medical treatment)	[2005] 1 All ER 387	Eng
North Western Health Board v HW	[2001] 3 IR 622	Irl
O'Keefe v Kulcullen High Court	High Court (O'Sullivan J) 24 June 1998	Irl
O'Laoire v Medical Council	High Court (Keane J) 27 January 1995	Irl
O'Donovan v Cork County Council	[1967] IR 173	Irl
O'Reilly v Limerick Corporation	[1989] ILRM 181	Irl
Perkins v Lavin	(1994) 648 NE 2d 840	US
Pretty v United Kingdom	(2002) 35 EHRR 1	ECtHR
Prince v Massachusetts	(1944) 331 US 158	US
Procanik v Cillo	(1984) 478 A 2d 755	US
R (Burke) v General Medical Council	[2004] EWHC 1879 (Admin)	Eng
R v Stone and Dobinson	[1977] QB 358	Eng
Rasmussen v Fleming	(1987) 154 Ariz 207	US
Re AK (medical treatment: consent)	[2001] 1 FLR 129	Eng

Re B (adult: refusal of medical treatment)	[2002] 2 All ER 449	Eng
Re C (adult: refusal of medical treatment)	[1994] 1 All ER 819	Eng
Re F (Mental Patient: Sterilisation)	[1989] 2 All ER 545	Eng
Re Martin	538 NW2d (Mich 1995) 229	US
Re MB (medical treatment)	[1997] 2 FLR 426	Eng
Re Quinlan	(1976) 355 A2d 647 (NJ)	US
Re R (a minor) (blood transfusion)	[1993] 2 FLR 757	Eng
Re R (a minor) (wardship: medical treatment)	[1991] 4 All ER 177	Eng
Re R (adult: medical treatment)	[1996] 2 FLR 99	Eng
Re T (adult: refusal of medical treatment)	[1992] 4 All ER 649	Eng
Re W (a minor) (medical treatment)	[1992] 4 All ER 627	Eng
Roelen v Akron Beacon Journal	(2002) 199 F Supp 2d 685	US
Schloendorff v Society of New York Hospital	(1914) 105 NE 92	US
Sinnott v Minister for Education	[2001] 2 IR 545	Irl
Smith v Cote	(1986) 513 A2d 341	US
The People (DPP) v JT	(1988) 3 Frewen 141	Irl
Turpin V Sortini	(1982) 182 Cal Rptr 337	US
W Healthcare NHS Trust v H	[2005] 1 WLR 834	Eng
W v Ireland (No 2)	[1997] 2 IR 141	Irl
Wilkinson v Downton	[1897] 2 QB 57	Eng

INTRODUCTION

A Background to the project

1. This Consultation Paper forms part of the Commission's *Third Programme of Law Reform 2008-2014*.¹

2. The Commission has previously addressed the topic of advance care directives in the following:

- *Report on Vulnerable Adults and the Law* (2006);²
- *Consultation Paper on Vulnerable Adults and the Law: Capacity* (2005);³
- *Consultation Paper on Law and the Elderly* (2003).⁴

In the *Consultation Paper on Law and the Elderly*, the Commission acknowledged that there has been no legislation or case law in Ireland specifically addressing the efficacy of advance care directives. It suggested that "since it is possible to nominate another person to make personal and property decisions, it ought to be possible to make those decisions oneself and have them carried out by others if incapacity sets in. They could provide for practical decisions in relation to personal care and property – broadly the same issues as may be dealt with under an EPA."⁵ However, the Commission was aware of the important and contentious moral, legal and ethical questions raised by advance care directives and that such questions would require detailed consideration.⁶

¹ See *Report on the Third Programme of Law Reform 2008-2014* (LRC 86-2007). Project 30 in the Third Programme commits the Commission to examine "Legal Aspects of Bioethics".

² Law Reform Commission *Report on Vulnerable Adults and the Law* (LRC 82-2006) at paragraph 3.36.

³ Law Reform Commission *Consultation Paper on Vulnerable Adults and the Law: Capacity* (LRC CP 37-2005) at paragraphs 7.63-7.64.

⁴ Law Reform Commission *Consultation Paper on Law and the Elderly* (LRC CP 23-2003) at paragraphs 3.48-3.51.

⁵ *Ibid* at paragraph 3.48.

⁶ *Ibid* at paragraph 3.51.

The Commission therefore confined itself to noting that the subject was one which may “merit further consideration in the context of the establishment of a coherent legal framework for capacity and substitute decision-making.”⁷

3. In the 2006 *Report on Vulnerable Adults and the Law*, the Commission acknowledged the public consultation conducted by the Irish Council for Bioethics on the legal and ethical issues surrounding advance care directives with a view to publishing an opinion on the subject. The opinion, *Is It Time for Advance Healthcare Directives?* was published in February 2007.⁸

B Introduction to advance care directives

4. This Consultation Paper deals with the situation where a person consciously sets out their wishes about what should happen to them in the event of an accident (such as a serious car crash) or illness (such as stroke or the onset of Alzheimer’s disease) that makes it impossible for them to communicate their wishes directly. The Commission is conscious that not many people do this,⁹ just as not as many people who should make a will or take out a pension actually do it. For those who have taken the trouble to plan what should happen to them in the future (which the Commission would, of course, encourage) it is possible that the person may decide to deal with a range of issues, including their property and health care, in a single document. This document may also include the appointment of a person – often a family member – to carry out their wishes. The person appointed is sometimes called a proxy or attorney – the person confers a ‘power of attorney’ on this proxy or agent to act on the person’s behalf.

5. Under current Irish law, contained in the *Powers of Attorney Act 1996*,¹⁰ a person may confer such a power of attorney in connection with property only. The Commission has recommended that the 1996 Act be extended to include the ability to grant power of attorney in connection with

⁷ Consultation Paper on *Vulnerable Adults and the Law: Capacity* (LRC CP 37-2005) at paragraph 7.64.

⁸ Available at www.bioethics.ie.

⁹ In a study conducted in 2003, 27% of physicians had experienced advance directives for Irish patients: Fennell Butler Saaidin Sheikh “Dissatisfaction with Do Not Attempt Resuscitation Orders: A Nationwide Study of Irish Consultant Physician Practices” (2006) 99(7) *Irish Medical Journal* 208.

¹⁰ The 1996 Act implemented the Commission’s *Report on Land Law and Conveyancing Law (2): Enduring Powers of Attorney* (LRC 31-1989).

minor health care decisions¹¹ and the Government intends to bring forward legislation to implement this recommendation.¹² This proposed change to the 1996 Act would provide one mechanism by which advance care directives could be regulated by law.

6. The Commission is aware, of course, and discusses this in detail in this Consultation Paper, that advance care directives can often also take the form of a verbal statement, especially in reply to a series of questions when a person is suddenly admitted to hospital and they do not have a written advance directive to hand. In that respect, changes to the law on powers of attorney will not deal with all circumstances in which advance care directives may arise.

C The absence of a legal framework

7. It is clear that, at present, there is no formal legal structure to deal with advance care directives in general. The Commission is conscious that this has not prevented those who have thought about their future care from stating their wishes verbally or in writing. In other words, it is important for the Commission to note that there is no law prohibiting a person from setting out their wishes, and that some have, and that the medical profession has attempted to deal with this in the absence of a clear legal framework.

8. The Commission's primary concern in this respect, therefore, is to acknowledge that this is being done in the absence of a clear legal framework and that those directly affected – the person stating their wishes verbally or in writing and the medical personnel who already try to fulfil these wishes to the best of their abilities – should be provided with a clear legal framework for the future.

D Scope of the project

9. The Commission is especially conscious that this Consultation Paper centres on medical treatment that will affect the life of the person concerned. It deals with complex legal and ethical issues which have created enormous debate nationally and internationally.

10. The Commission wishes to make clear from the outset what this Consultation Paper does not deal with. It is not concerned with the debate about

¹¹ Law Reform Commission *Report on Vulnerable Adults and the Law* (LRC 83-2006) at paragraph 4.32.

¹² In September 2008, the Government published a *Scheme of Mental Capacity Bill 2008*, Head 48 of which proposes to allow an attorney to make health care decisions: available at www.justice.ie.

whether current criminal law on homicide or suicide should be changed. This Consultation Paper is not, therefore, concerned with euthanasia. The Commission is of the clear view that any steps taken to hasten death in a manner that would, under current law, amount to murder or to assisting suicide will not in any way be affected by the proposals being considered in this Consultation Paper.

11. Nor does this Consultation Paper include psychiatric advance care directives. Psychiatric advance care directives offer individuals suffering from a mental illness a practical means to express their treatment preferences in writing. “By engaging the person in the process of deliberating on their illness history and the factors, including medication, that had been effective during previous psychiatric episodes, it is believed advance directives could improve the therapeutic alliance between clinicians and patient and may improve the person’s treatment adherence with its consequent benefits in terms of quality of life and reduced need for hospitalisation.”¹³ The most controversial form of psychiatric advance directive is what is commonly referred to as the Ulysses directive. It enables individuals to bind themselves to psychiatric treatment and override, in advance, their refusals during acute episodes of their illness. The name references the Odyssey, in which Ulysses directed his crew to tie him to the ship’s mast and leave him bound as the ship approached the Sirens, regardless of his subsequent pleas to cut him loose.¹⁴

12. The English *Mental Capacity Act 2005* and the Scottish *Mental Health (Care and Treatment) (Scotland) Act 2003* contains no provision for a person to use advance decisions to express a positive preference for particular forms of treatment. It has been argued that this represents a missed opportunity to allow patients and healthcare professionals to “engage in a more constructive approach to treatment planning.”¹⁵ The *Mental Health (Care and Treatment) and the (Scotland) Act 2003* gives some recognition to the concept of advance directives in psychiatry by requiring tribunals and mental health professionals to “have regard” to their terms. The Scottish executive was not prepared to accept that the compulsory powers in mental health legislation could be overruled by a

¹³ Exworthy “Psychiatric Advance Decisions – An Opportunity Missed” (2004) *Journal of Mental Health Law* 129. See also Sheetz “The Choice to Limit Choice: Using Psychiatric Advance Directives to Manage the Effects of Mental Illness and Support Self-Responsibility” (2006) 40 *U Mich J L Reform* 401; Gevers “Advance Directives in Psychiatry” (2002) 9 *European Journal of Health Law* 19; Dunlap “Mental Health Advance Directives: Having One’s Say?” (2001) *Kentucky Law Journal* 327.

¹⁴ Homer *The Odyssey* Book XII, lines 177-83.

¹⁵ *Ibid* at 134.

psychiatric advance directive made by a competent person. It was felt that the time was not right for such a radical approach.¹⁶ Given the complexities involved, the Commission has concluded that it should confine its analysis to advance care directives that do not involve mental health. The Commission may return to this area at a future date.

E Outline of this Consultation Paper

13. In Chapter 1, the Commission discusses the origins and nature of advance care directives. The Commission also reiterates that this Consultation Paper does not address euthanasia or assisted suicide. The Commission discusses the terminology, such as 'living wills', associated with advance care directives. This Chapter also notes the different forms of directives, both in terms of the difference between negative advance care directives and positive advance care directives and also that some can be written but can also be given verbally, especially in a hospital admissions setting. The Commission discusses the use of Enduring Powers of Attorney (EPAs) and, more widely, a healthcare proxy in connection with advance care directives.

14. In Chapter 2, the Commission explores in some detail the legal basis for recognising advance care directives, notably how the constitutional right to refuse treatment in Irish law provides a framework for advance care directives. The Commission also discusses the various types of legal frameworks that have emerged in a number of States; this includes a consideration of whether fundamental principles and policies concerning advance care directives should be embodied in legislation or in non-statutory ethical guides. The Commission's analysis includes a consideration of advance care directives that refuse treatment on religious grounds, an issue that was addressed recently in a High Court case.

15. In Chapter 3, the Commission discusses informed decision-making and the capacity to make advance care directives. The Commission assesses the importance of ensuring that any medical treatment decision, whether contemporaneous or anticipatory, is sufficiently informed and whether it should be a mandatory requirement to receive advice while drafting an advance care directive. The Commission addresses capacity in general terms and also in the specific context of the age at which a person should be considered competent to refuse treatment in an advance care directive setting.

16. In Chapter 4, the Commission considers a number of specific formalities concerning advance care directives. The Commission begins by

¹⁶ Patrick "Scottish Parliament acts on Mental Health Law Reform" (2003) *Journal of Mental Health Law* 71, at 74.

discussing whether an advance care directive should always be in writing or whether this might be limited to certain types, such as those that refuse life-sustaining treatment. The Commission also discusses: whether an advance care directive should be witnessed, whether it should be in a prescribed form, what requirements should apply to determine its validity, in what circumstances is it deemed to be activated (the “triggering event”), what should happen when a person attempts to revoke an advance care directive, whether an advance care directive be subject to regular review and whether a central filing system for advance care directives should be considered.

17. In Chapter 5, the Commission concludes the Consultation Paper by discussing the legal consequences for health care professionals of not complying with the terms of an advance care directive that meets the criteria set out by the Commission. The Commission sets out the current law, particularly in terms of medical treatment given without consent (and where the doctrine of medical necessity does not apply). While the current law provides a series of defences where liability is at issue, notably, that the medical professional acted on an advance care directive, the Commission considers that a statutory framework should underpin current practice and deal with difficult gaps. The Commission outlines the possible models that might be considered in this respect.

18. This Consultation Paper is intended to form the basis of discussion and therefore all the recommendations made are provisional in nature. The Commission will make its final recommendations on the subject of advance care directives following further consideration of the issues and consultation with interested parties. Submissions on the provisional recommendations included in this Consultation Paper are welcome. To enable the Commission to proceed with the preparation of its Final Report, those who wish to do so are requested to make their submissions in writing by post to the Commission or by email to info@lawreform.ie by 31 January 2009.

CHAPTER 1 ORIGINS AND NATURE OF ADVANCE CARE DIRECTIVES

A Introduction

1.01 In this Chapter, the Commission discusses the origins and nature of advance care directives. In Part B, the Commission first discusses a general definition, namely, that a person consciously setting down their wishes about what should happen to them in the event of an accident or illness that makes it impossible for them to communicate their wishes directly. In Part C, the Commission discusses the origins of advance care directives in the context of medical outcomes. In Part D, the Commission discusses the terminology, such as 'living wills', associated with advance care directives. In Part E, the Commission reiterates that the Consultation Paper does not address either euthanasia or assisted suicide and also turns to the different forms of directives notably in terms of the difference between negative advance care directives and positive advance care directives. In Part E the Commission also discusses the form of advance care directives, some of which can be written but which can also be given verbally, especially in a hospital admissions setting. The Commission examines, in particular, the extent negative advance care directives are, in practice, capable of being brought within a suitable legal framework. In Part F, the Commission discusses Enduring Powers of Attorney (EPAs) and, more widely, the use of a healthcare proxy in connection with advance care directives.

B Definition

1.02 In general terms, an advance care directive "involves an individual making a decision or series of decisions on future medical treatment which is designed to take effect should the person lack the requisite capacity to make the relevant decision at a future date."¹

1.03 Section 24(1) of the English *Mental Capacity Act 2005* defines an advance decision as a decision made by a person, after he or she has reached 18 and when he or she has capacity to do so, that if –

¹ Law Reform Commission *Report on Vulnerable Adults and the Law* (LRC 82-2006) at paragraph 3.36.

- “(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.”

1.04 This provision “contains considerable flexibility and carries considerable power.”² The author of the advance decision can specify the treatments at issue, and specify any conditions for its application. It applies to the commencement and the continuation of treatment. However, section 24(1) of the English 2005 Act refers only to advance refusals of treatment. An advance decision cannot require a treatment provider to offer a specific treatment.

C The origin of advance care directives

1.05 The issues of death and dying have become matters of worldwide public debate in recent years and came to the fore in Ireland in *In re a Ward of Court (No 2)*.³ In his dissent in the US Supreme Court decision of *Cruzan v Director Missouri Department of Health*,⁴ Stevens J submitted that two factors were responsible for this development: first, the environment in which the process of dying occurs is no longer in the private setting of one’s home, but has moved to the more public setting of healthcare institutions; second, advances in medical technology have made it possible to indefinitely prolong the lives of terminally ill patients, merging body and machine in a manner that “some might reasonably regard as an insult to life rather than as its continuation.” The Supreme Court of Arizona described this development in *Rasmussen v Fleming*:

“Not long ago the realms of life and death were delineated by a bright line. Now this line is blurred by wondrous advances in medical technology – advances that until recent years were only ideas conceivable by such science-fiction visionaries as Jules Verne and HG Wells. Medical technology has effectively created a twilight zone of suspended animation where death commences while life, in some

² Bartlett *Blackstone’s Guide to the Mental Capacity Act 2005* (Oxford University Press 2005) at paragraph 2.101.

³ [1996] 2 IR 79

⁴ (1990) 497 US 261 cited in *In re a Ward of Court (withholding medical treatment) (No 2)* [1996] 2 IR 79 at 133-134.

form, continues. Some patients, however, want no part of a life sustained only by medical technology. Instead, they prefer a plan of medical treatment that allows nature to take its course and permits them to die with dignity.

As more individuals assert their right to refuse medical treatment, more frequently do the disciplines of medicine, law, philosophy, technology and religion collide. This interdisciplinary interplay raises many questions to which no single person or profession has all the answers.”⁵

1.06 The idea of advance care treatment decision-making therefore emerged not only as a response to the fear of many that they would become prisoners “trapped by medicine’s ever-expanding ability to sustain life indefinitely after they lose the ability to voice their wishes about treatment at the end of life”⁶, but also as an acknowledgement of patient autonomy as the paramount principle in bioethics. In this respect it is important to note that, as was discussed in the *Ward of Court* case, dying is a natural part of life and of living. An advance care directive may therefore be seen as an expression of a person’s wishes about how their medical treatment impacts on the quality of this part of living.

1.07 Bioethics “asks difficult moral questions and provides decision-makers with principles to guide them to answers”⁷ and Beauchamp and Childress formulated four such principles – respect for autonomy, non-maleficence, beneficence and justice.⁸ The central tenet of the Hippocratic Oath is based on the principle of beneficence – to do good. In its earliest formulation, the Oath dealt with the fundamental idea of ‘benefit’ for the patient and it required doctors to:

“... keep this oath... for the benefit of my patients and abstain from whatever is deleterious and mischievous... with purity and with

⁵ (1987) 154 Ariz 207 cited in *Re a Ward of Court (No 2)* [1996] 2 IR 79 at 131 per O’Flaherty J.

⁶ Capron “Advance Directives” in Kuhse and Singer (eds) *A Companion to Bioethics* (Blackwell Publishing 1998) at 262.

⁷ Rosato “Using Bioethics Discourse to Determine When Parents Should Make Health Care Decisions for Their Children: Is Deference Justified?” (2000) 73 *Temple Law Review* 1 at 29.

⁸ Beauchamp and Childress *Principles of Biomedical Ethics* (5th ed Oxford University Press 2001).

holiness I will pass my life and practice my Art... I will not divulge... all such should be kept secret.”⁹

1.08 Conversely, the principle of non-maleficence is the duty not to harm and echoes the law’s duty of care.¹⁰ This principle of justice has been described as the “moral obligation to act on the basis of fair adjudication between competing claims.”¹¹

1.09 The principle of autonomy derives from the Greek *autos* (self) and *nomos* (rule or law) and has come to refer to “personal self-governance; personal rule of the self by adequate understanding while remaining free from controlling interferences by others and from personal limitations that prevent choice.”¹² The importance of autonomy as a value in medical law extends back at least to the judgment of Cardozo J in *Schloendorff v Society of New York Hospital*, where he stated that:

“Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient’s consent commits an assault, for which he is liable in damages.”¹³

1.10 Historically, health care was provided in a paternalistic environment where physicians knew what was best for their patients. However, from the late 1950’s continuing through the early 1970’s, paternalism became popularly unacceptable, with patients demanding to play a more active role in their medical care with the prevailing ethos that ‘doctor does not necessarily know best.’

1.11 In 1969, Luis Kutner, a US attorney active in a right-to-die organisation, drafted the first ‘living will’ which allowed a person to give instructions for medical care in the final days of life. His proposal was that a competent adult should be able to execute a document “analogous to a revocable or conditional trust, with the patient’s body as the res (the property or

⁹ Chalmers “International Medical Research Regulation: From Ethics to Law” in McLean (ed) *First Do No Harm* (Ashgate 2006) 81 at 83.

¹⁰ Brazier “Do No Harm – Do Patients Have Responsibilities Too?” (2006) 65(2) *Cambridge Law Journal* 397 at 399.

¹¹ Madden *Medicine, Ethics & the Law* (Tottel Publishing 2002) at paragraph 1.81.

¹² Faden and Beauchamp *A History and Theory of Informed Consent* (Oxford University Press 1986) at 8.

¹³ (1914) 105 NE 92.

asset), the patient as the beneficiary and grantor, and the doctor and hospital as trustees.”¹⁴

D Terminology

1.12 The terms ‘living will’ and ‘advance directive’ are employed interchangeably throughout US literature and it appears that any distinction is largely academic. The term ‘living will’, however, was specifically denounced as “misleading” by Munby J in *HE v A Hospital NHS Trust* on the basis that:

“The *Wills Act 1837* does not apply to an advance directive. An advance directive does not need to be in writing and signed, nor need it be attested by witnesses. Nor, unlike a will, can an advance directive be revoked only by physical destruction or by another document in writing.”¹⁵

1.13 In its *Consultation Paper on Mentally Incapacitated Adults and Decision-Making*,¹⁶ the Law Commission for England and Wales viewed the terms ‘living will’ and ‘advance directive’ as two distinct concepts, and explained the distinction as follows:

“Advance directives are usually discussed in the context of medical treatment and relate mainly to the patient’s right to refuse or change treatment in a disabling chronic or terminal illness.”¹⁷

In contrast, a ‘living will’ is defined as:

“... essentially a formal declaration by a competent adult expressing the wish that if he becomes so mentally or physically ill that there is no prospect of recovery, any procedures designed to prolong life should be withheld. The object is to rebut any presumption that the patient has consented to treatment which may be administered under the doctrine of necessity, and to give the patient power to direct in advance the treatment, or lack of treatment, that he wishes to receive at the end of his life should he lose the ability to do so at the time.”¹⁸

¹⁴ Kutner “Due Process of Euthanasia: The Living Will, A Proposal” (1969) 44 *Indiana Law Journal* 539 at 552.

¹⁵ [2003] EWHC 1017; [2003] 2 FLR 408 at paragraph 35.

¹⁶ Law Commission for England and Wales *Consultation Paper on Mentally Incapacitated Adults and Decision-Making: An Overview* (No 119 1991).

¹⁷ *Ibid* at paragraph 6.2.

¹⁸ *Ibid* at paragraph 6.5.

1.14 In other words, the Law Commission for England and Wales viewed a living will as dealing only with advance instructions prohibiting treatment to prolong the individual's life where there was no prospect of recovery. An advance directive, however, was wider in scope, going to the nature of the treatment to be withheld, and the identification of any persons authorised to make decisions on the individual's behalf. In its *Report on Mental Incapacity*, the Law Commission for England and Wales did not make a similar distinction. It felt that the terms 'living will' and 'advance directive' focused attention on the existence and terms of a piece of paper. Instead, it preferred to distinguish between an 'advance expression of views and preferences' on the one hand and an 'advance decision' on the other. It recommended that only an 'advance decision' should have legal effect.¹⁹

1.15 The Law Reform Commission of Hong Kong refused to engage in a terminology debate, arguing instead that the only relevant distinction to be drawn is between those situations in which the individual has given an advance indication of his or her wishes before the onset of incapacity (as in the case of living wills or advance directives) and those in which he or she has not (as in the case of comatose patients).²⁰

1.16 The Irish Council for Bioethics chose to adopt the term 'advance healthcare directive'.²¹ Queensland legislation governing advance care directives uses the term 'advance health directive'.²² Singapore's legislation uses the term 'advance medical directive'.²³ The National Medical Ethics Committee (NMEC) of Singapore added the word 'medical' to clearly delimit the use of the directive to instructions on medical treatment only. It preferred the term 'advance medical directive' over 'living will' as the latter term denotes death, whereas the former term is "intended to allow a person to retain autonomy over his medical management when he is terminally ill and incompetent."²⁴

¹⁹ Law Commission for England and Wales *Report on Mental Incapacity* (No 231 1995) at paragraph 5.1.

²⁰ Law Reform Commission of Hong Kong *Consultation Paper on Substitute Decision-Making and Advance Directives in Relation to Medical Treatment* (2004) at 137.

²¹ *Is it Time for Advance Healthcare Directives?* (Irish Council for Bioethics 2007).

²² *Powers of Attorney Act 1998* (Qld).

²³ *Advance Medical Directive Act 1996* (Singapore).

²⁴ Leng and Sy "Medical Directives in Singapore (1997) 5 *Medical Law Review* 63 at 75.

1.17 While the Commission does not wish to engage in a terminology debate, it is of the opinion that advance care directives should not be limited and should cover all forms of medical care. To ensure moreover, that people can retain autonomy over their medical care in the event of incapacity, the Commission does not believe that advance care directives should be confined, for example, to situations in which death is imminent.

1.18 *The Commission provisionally recommends that the term “Advance Care Directive” be adopted.*

E Scope of advance care directives

(1) Homicide, euthanasia, assisted suicide

1.19 Euthanasia is illegal in Ireland and constitutes either murder or, perhaps, involuntary manslaughter. Therefore, an advance care directive should not enable a patient to make demands which he or she could not lawfully have made when capable.

1.20 It is important to understand the difference between advance care directives refusing life-sustaining treatment and assisted suicide. To quote Lord Goff in the English case of *Airedale NHS Trust v Bland*:²⁵

“... 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 do, declined to consent to treatment which might or would have the effect of prolonging his life, and the doctor has, in accordance with his duty, complied with his patient’s wishes.”²⁶

He added that this is so regardless of whether the refusal is contemporaneous, or anticipatory:

“Moreover the same principle applies where the patient’s refusal to give his consent at an earlier date before he became unconscious or otherwise incapable of communicating it, though in such circumstances, special 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.”²⁷

1.21 In England and Wales, a draft *Mental Incapacity Bill* published in 2003 had been subjected to pre-legislative scrutiny by a Joint Committee of the

²⁵ [1993] 1 All ER 82.

²⁶ *Ibid* at 866.

²⁷ *Ibid*.

two Houses of Parliament. Many of the submissions to the Joint Committee were concerned with advance decisions which provided for the withdrawal of life-sustaining treatment.²⁸ The Committee rejected the argument that this would “bring euthanasia a step closer”; instead regarding an advance care directive as an “appropriate continuation of respect for a patient’s individual autonomy.”²⁹ Section 62 of the *Mental Capacity Act 2005* specifically states that the criminal laws relating to homicide, euthanasia and assisted suicide are unchanged by the Act. Similarly the Commission is of the opinion that any introduction of legislation regarding advance care directives in this jurisdiction should not affect the laws on euthanasia and assisted suicide. In that respect the Commission emphasises that this Consultation Paper and project will not affect these aspects of current law.

(2) Negative advance care directives v positive advance care directives

1.22 As medical technology developed, patients invoked the autonomy argument to refuse treatment that merely prolonged the dying process. In effect, patients were informing physicians through advance care directives that, “treatment that could not return them to an acceptable quality of life was futile.”³⁰ More recently, a logical extension (or what others have termed a “darker side”)³¹ of the autonomy argument has emerged: namely, that one should respect the wishes of a person who has executed an advance care directive *not* to stop life-sustaining treatment, even if such treatment is futile.

1.23 However, it has been argued that the right to self-determination is a misnomer, as one does not have a right to determine what *shall* be done to one’s own body; rather, there is only a right to determine what shall *not* be done

²⁸ Exworthy “Psychiatric advance decisions – an opportunity missed” (2004) *Mental Health Law* 129 at 138.

²⁹ House of Lords, House of Commons Joint Committee on the Draft Mental Incapacity Bill (2003) Session 2002 03. Volume I. HL Paper 189-1, HC 1083-1. London: The Stationery Office at paragraph 199.

³⁰ Pripp and Moretti, “Medical Futility: A legal perspective” in Zucker and Zucker (eds) *Medical Futility and the Evaluation of Life-Sustaining Interventions* (Cambridge University Press, 1997) 136 at 137.

³¹ Jecker “Being a Burden on Others” in Capron (ed) “Medical Decision Making and ‘The Right to Die’ after Cruzan” (1991) 19 *Law Medicine and Health Care* 16 at 19.

to one's body.³² Consequently, there is an important distinction between positive advance care directives and negative advance care directives. The Commission agrees with the view that an individual has a constitutional right to refuse medical treatment. By contrast, it appears that a positive right to be treated only arises in specific medical contexts such as immunisation of children against disease.³³ In its ethical guidelines, the Irish Medical Council has stated that:

“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 a treatment which is futile or disproportionately burdensome. Deliberately causing the death of a patient is professional misconduct.”³⁴

1.24 As a result, advance care directives should provide that a patient can refuse, but not request, treatment. Examples 1 to 4 below are examples of refusals of treatment that would be recognised in an advance care directive, as opposed to the requests for treatment as outlined in examples 5 to 7. As Pripp and Moretti have noted, the “difference between the demands ‘don’t touch me’ and ‘you must touch me’ is dramatic.”³⁵

- *Example 1:*

“I do not wish to receive a blood transfusion.”

- *Example 2:*

“I do not wish to receive a flu injection.”

- *Example 3:*

“I do not wish to be resuscitated.”

³² Munby “Rhetoric and Reality: The Limitations of Patient Self-Determination in Contemporary English Law” (1998) 14 *Journal of Contemporary Health Law and Policy* 315 at 322.

³³ Madden *Medicine, Ethics & the Law* (Tottel Publishing 2002) at paragraph 11.29.

³⁴ Irish Medical Council *A Guide to Ethical Conduct and Behaviour* (6th ed 2004) at paragraph 23.1.

³⁵ Pripp and Moretti, “Medical Futility: A legal perspective” in Zucker and Zucker (eds) *Medical Futility and the Evaluation of Life-Sustaining Interventions* (1997) 136 at 139. See also Bagheri “Regulating Medical Futility: Neither Excessive Patient’s Autonomy Nor Physician’s Paternalism” (2008) 15 *European Journal of Health Law* 45.

- *Example 4:*
“I do not wish to receive artificial nutrition and hydration if I fall into a coma.”
- *Example 5*
“I want morphine when I am in great pain.”
- *Example 6*
“I want a liver transplant.”
- *Example 7*
“I want a drug that is available in a clinical trial in the Mayo Clinic.”

(a) *England and Wales*

(i) *Mental Capacity Act 2005*

1.25 The Law Commission of England and Wales noted that a matter of great concern for medical practitioners was that an advance care directive could force them to do something which would conflict with their clinical judgment.³⁶ Section 24 of the English *Mental Capacity Act 2005* has responded to these concerns by legislating only for refusals of treatment – the Act does not provide that a patient can request treatment. A person may state his treatment preferences, but such views will merely go “into the mix of factors to be considered in a best interests determination.”³⁷

(ii) *Burke case*

1.26 Over the last fifty years, autonomy has become the bedrock of medical law. However, some would argue that autonomy has “gradually but inexorably extended to become a claim of a right to health care”, ushering in a new era of patient-consumerism wherein the doctor must deliver what the patient demands.³⁸ The English High Court decision in *R (Burke) v General*

³⁶ Law Commission for England and Wales *Report on Mental Incapacity* (No 231 1995) at paragraph 5.28.

³⁷ Bartlett *Blackstone’s Guide to the Mental Capacity Act 2005* (2nd ed Oxford University Press, 2008) at paragraph 2.104.

³⁸ Brazier “Do No Harm – Do Patients Have Responsibilities Too?” (2006) 65(2) *Cambridge Law Journal* 397 at 400.

*Medical Council*³⁹ contributed to this perception of the primacy of autonomy. The applicant had cerebellar ataxia, a degenerative brain illness which had already paralysed him from the neck down, and would eventually paralyse the rest of his body. His condition would deteriorate to the point where he would be entirely dependent upon others, and will need artificial nutrition and hydration (ANH) to survive. However, he was likely to retain full cognitive faculties until the final stages of his condition. He sought clarification of the circumstances when ANH may lawfully be withdrawn. His fear was that the guidelines allowed doctors to withdraw treatment, while the patient still wished to live, leading to death by starvation or thirst. The relevant sections of the General Medical Council's guidance were as follows:

“If you are the consultant or general practitioner in charge of a patient's care, it is your responsibility to make the decision about whether to withhold or withdraw a life-prolonging treatment, taking account of the views of the patient or those close to the patient...”⁴⁰

“Where death is not imminent, it usually will be appropriate to provide artificial nutrition and hydration. However, circumstances may arise where you judge that a patient's condition is so severe, the prognosis is so poor, and that providing artificial nutrition and hydration may cause suffering or be too burdensome in relation to the possible benefits.”⁴¹

The applicant therefore contended that where competent patients request or where incompetent patients have, prior to becoming incompetent, made it clear that they would wish to receive artificial nutrition and hydration, the withholding or withdrawal of such treatment, leading to death by starvation or thirst, would be a breach of their rights under Articles 2, 3 and 8 of the European Convention on Human Rights.⁴²

1.27 In the English High Court, Munby J declared that the GMC guidance was unlawful, on the grounds that it placed the emphasis throughout on the right of the competent patient to refuse treatment rather than on his right to require treatment; failed to acknowledge the heavy presumption in favour of life-prolonging treatment; and was incompatible with the claimant's rights under

³⁹ [2004] EWHC 1879 (Admin) at paragraph 166.

⁴⁰ General Medical Council *Withholding and Withdrawing Life-Prolonging Treatments: Good Practice in Decision-Making* (GMC 2002) at paragraph 32.

⁴¹ *Ibid* at paragraph 81.

⁴² Article 2 (the right to life); Article 3 (protection against degrading treatment); Article 8 (respect for private and family life).

common law and under Articles 2, 3 and 8 of the Convention.⁴³ The judgment of Munby J was “path-breaking” in recognising the ability of competent patients to require life-prolonging treatment either contemporaneously, or by way of an advance care directive:⁴⁴

“... the personal autonomy protected by Article 8 means that in principle it is for the competent patient, and not his doctor, to decide what treatment *should or should not* be given in order to achieve what *the patient* believes conduces to his dignity and in order to achieve what the patient would find distressing.”⁴⁵

“If the patient is competent (or, although incompetent, has made an advance directive which is both valid and relevant to the treatment in question), his *decision to require* the provision of ANH which he believes is necessary to protect him from what he sees as acute mental and physical suffering is likewise in principle determinative. There are, as it seems to me, two separate reasons why this is so. The first is based on the competent patient’s rights under Article 8. The second is based on his rights, whether competent or incompetent under Article 3.”⁴⁶

1.28 The judgment in *Burke* provoked some controversy.⁴⁷ Mason and Laurie argued that Munby J’s suggestion that the case had no significant cost implications was utterly unrealistic given that “the costs of providing even basic care, over a sustained period of time, and with attendant staffing costs, must represent a significant impact on the finite resources of a national health

⁴³ *R (Burke) v General Medical Council* [2004] EWHC 1879 (Admin) at paragraph 166. See Gurnham “Losing the Wood for the Trees: Burke and the Court of Appeal” (2006) 14 *Medical Law Review* 253 at 255.

⁴⁴ Fennell “United Kingdom: The Right to Require Life-Prolonging Treatment” (2004) 12(3) *Medical Law Review* 306 at 315.

⁴⁵ *R (on the application of Burke) v General Medical Council* [2004] EWHC 1879 (Admin) at paragraph 166.

⁴⁶ *Ibid* at paragraph 169.

⁴⁷ Mason and Laurie “Personal Autonomy and the Right to Treatment: A Note on *R (on the application of Burke) v General Medical Council*” (2004-2005) 9 *Edinburgh Law Review* 123; Fennell “The Right to Require Life-Prolonging Treatment” (2004) 12 *Medical Law Review* 306; Merchant “The Right to Treatment” (2004) *New Law Journal* 1316; Gillon “Why the GMC is Right to Appeal Over Life-Prolonging Treatment” (2004) 329 *British Medical Journal* 810.

service.”⁴⁸ More importantly, however, Munby J’s failure to distinguish clearly between the provision of artificial nutrition and hydration and the treatment of terminal illness in general sparked fears that a general right to request treatment had been established that was potentially “applicable across the whole spectrum of medical care of the terminally ill.”⁴⁹

1.29 On appeal in the *Burke* case, the English Court of Appeal unanimously upheld the GMC’s appeal and declared the guidance lawful.⁵⁰ It suggested that, at times, Munby J might have “lost the wood for the trees”⁵¹ and that it would be “inappropriate to leave the judgment to be seized on and dissected by lawyers seeking supportive material for future cases.”⁵² In the Court’s opinion, Mr Burke had not made an advance care directive and, therefore, Munby J should not have declared that an advance care directive requesting life-prolonging treatment should be complied with as a matter of law. It observed that this would be incompatible with the English *Mental Capacity Act 2005* which only requires that a request for treatment in an advance decision be taken into consideration when considering what is in the best interests of a

⁴⁸ Mason and Laurie “Personal Autonomy and the Right to Treatment: A Note on *R (on the application of Burke) v General Medical Council*” (2004-2005) 9 *Edinburgh Law Review* 123 at 131.

⁴⁹ Mason and Laurie “Personal Autonomy and the Right to Treatment: A Note on *R (on the application of Burke) v General Medical Council*” (2004-2005) 9 *Edinburgh Law Review* 123 at 123. See also Gillon “Why the GMC is Right to Appeal Over Life-Prolonging Treatment” (2004) 329 *British Medical Journal* 810.

⁵⁰ *R (Burke) v General Medical Council* [2005] EWCA Civ; [2005] 2 FLR 1223. See Biggs “‘Taking Account of the Views of the Patient’, but only If the Clinician (and the Court) Agrees – *R(Burke) v GMC*” (2007) 19(2) *Child and Family Law Quarterly* 225; de Cruz “The Burke Case: The Terminally Ill Patient and the Right to Life” (2007) 70(2) *Modern Law Review* 294; Gurnham “Losing the Wood for the Trees: Burke and the Court of Appeal” (2006) 14 *Medical Law Review* 253; McIvor “The Positive Medical Duty to Provide Life-Prolonging Treatment” (2006) *Professional Negligence* 59.

⁵¹ *R (Burke) v General Medical Council* [2005] EWCA Civ 1003; [2005] 2 FLR 1223 at paragraph 38.

⁵² *Ibid* at paragraph 24.

patient.⁵³ It acknowledged that parties do have a “paramount fight to refuse treatment”, but that “the corollary does not...follow.”⁵⁴

(b) United States of America

1.30 In the United States, widely diverging views are taken in relation to requests for treatment. A number of states have enacted legislation which gives health care providers authority to refuse requests for futile treatment. For example, Virginia’s *Health Care Decisions Act 1983* provides that health care providers are not required to provide medical treatment which is, in their opinion, medically or ethically inappropriate.⁵⁵ On the other hand, a number of states permit requests for treatment in an advance care directive. For example, Indiana recognises a legal right to receive medical treatment which can be communicated by a “Life Prolonging Procedures Declaration”. Indiana expressly permits requests for artificial nutrition and hydration “even if the effort to sustain life is futile or excessively burdensome.”⁵⁶ However, Pripp and Moretti have questioned whether this legislative right to request life-sustaining treatment creates a corresponding legal obligation to provide such treatment:

“Although it is unlikely that advance directive statutes would be interpreted as creating a positive right to receive any and all treatment, the legislatures that enacted these laws, as well as the individuals who rely on them, most likely believe they are protecting the patient’s right to be kept alive.”⁵⁷

(c) Ireland

1.31 While Article 40.3.1 of the Constitution of Ireland contains many unenumerated rights, the courts have never recognised a right to healthcare. While the State “has the duty of protecting the citizens from dangers to health in a manner not incompatible or inconsistent with the rights of citizens as human beings”⁵⁸ in the aftermath of *O’Reilly v Limerick Corporation*⁵⁹ and *Sinnott v*

⁵³ *Ibid* at paragraph 57.

⁵⁴ *Ibid* at paragraph 31. Note that the European Court of Human Rights unanimously rejected Mr Burke’s application, *Burke v United Kingdom* 19807/06

⁵⁵ *Health Care Decisions Act 1983*, Virginia Code § 54-1-2990.

⁵⁶ *Living Wills and Life-Prolonging Procedure Act 1985*, Indiana Code §16-36-4.

⁵⁷ Pripp and Moretti “Medical Futility: A Legal Perspective” in Zucker and Zucker (eds) *Medical Futility and the Evaluation of Life-Sustaining Interventions* (1997) 136 at 143.

⁵⁸ Per Ó Dalaigh J in *Ryan v Attorney General* [1965] IR 294 at 348.

⁵⁹ [1989] ILRM 181.

*Minister for Education*⁶⁰ it is unlikely that the courts would recognise a general right to health care. Yet, while a right to health care may not exist, “there is an absolute right in a competent person to refuse medical treatment even if it leads to death”.⁶¹ In this respect, the Commission provisionally concludes that advance care directives framed in a negative manner should form the basis for the statutory regime it proposes. The Commission discusses this in more detail in the succeeding sections of this chapter.

1.32 *The Commission provisionally recommends that negative advance care directives only should be regarded as legally binding.*

1.33 *An advance care directive is an advance indication of a person’s wishes that certain medical care is not to be given in the event that the patient becomes incompetent.*

(3) *What forms of treatment can be refused in an advance care directive?*

1.34 As noted by Sommerville,

“New ideas take time to permeate society. If society is serious about acknowledging patient rights and choices, including those expressed in advance, people need to become accustomed to anticipatory decision-making as a means of dealing with recurrent or familiar problems, rather than solely as a method for dealing with the frightening and the unusual.”⁶²

(a) *Treatment*

1.35 Section 24(1) of the English *Mental Capacity Act 2005* carries considerable power. It states that:

- (a) “if 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.”

⁶⁰ [2001] 2 IR 545.

⁶¹ *Re A Ward of Court* [1996] 2 IR 79 at 129.

⁶² Sommerville “Are Advance Directives Really the Answer?” in McLean (ed) *Death, Dying and the Law* (Dartmouth Publishing Company 1996) 29 at 35-36.

Therefore, a person can state that a specified treatment should not be commenced or continued in the event of incapacity.

(b) Withdrawal of life-sustaining treatment

1.36 The English *Mental Capacity Act 2005* also recognises the legality of advance decisions refusing life-sustaining treatment, so long as they are valid and applicable, and satisfy the conditions outlined in section 25.⁶³ If there is not a valid and applicable advance decision to refuse life-sustaining treatment, the decision whether to provide life-sustaining treatment is to be made in the ‘best interests’ of the patient.⁶⁴

1.37 In South Australia,⁶⁵ the Northern Territory,⁶⁶ and Singapore,⁶⁷ the scope of advance medical directives is restricted to the refusal of extraordinary life-sustaining measures in terminal cases.

1.38 Section 2 of Singapore’s *Advance Medical Directive Act 1996* defines ‘extraordinary life-sustaining treatment’ as:

“any medical procedure or measure which, when administered to a terminally ill patient, will only prolong the process of dying when death is imminent, but excludes palliative care.”⁶⁸

As the Singapore Act requires death to be imminent, irrespective of extraordinary measures, it would not permit the withdrawal of treatment from those in a persistent vegetative state because such patients can live on with

⁶³ See paragraphs 4.07 – 4.10 below.

⁶⁴ *Airedale NHS Trust v Bland* [1993] 1 All ER 821.

⁶⁵ *Consent to Medical Treatment and Palliative Care Act 1995* (SA).

⁶⁶ *Natural Death Act 1988* (NT).

⁶⁷ *Advance Medical Directives Act 1996* (Singapore). See Leng and Sy “Advance Medical Directives in Singapore” (1997) 5 *Medical Law Review* 63.

⁶⁸ ‘Terminal illness’ is defined in section 2 of the *Medical Directives Act 1996* as:

“an incurable condition caused by injury or disease from which there is no reasonable prospect of a temporary or permanent recovery where –

- (a) death would within reasonable medical judgment be imminent regardless of the application of extraordinary life-sustaining treatment; and
- (b) the application of extraordinary life-sustaining treatment would only serve to postpone the moment of death of the patient.”

artificial aids, such as being fed through nasogastric tubes.⁶⁹ Therefore, examples of ‘extraordinary life-sustaining treatment’ would include ventilators or cardiopulmonary resuscitation, but not dialysis, blood transfusions or resuscitation. However, difficulties of interpretation may arise, as ‘imminent’ is not defined by the *Advance Medical Directives Act 1996*. Death has been considered to be ‘imminent’ if occurring within timeframes ranging from 24 hours, to one week, to a few months at most.⁷⁰

1.39 While advance care directives must deal with life-sustaining treatment, the Commission considers that advance care directives should not be confined to end-of-life decisions.

(c) ‘Do Not Resuscitate’ orders: refusing cardiopulmonary resuscitation

(i) Background

1.40 A ‘Do Not Resuscitate’ order (DNR) is a doctor’s written order not to attempt cardiopulmonary resuscitation (CPR) on a particular patient.⁷¹ CPR was developed in the 1950’s for the purpose of restoring respiratory and cardiac functions to patients suffering a cardiac arrest. CPR was never intended to be administered to terminally ill patients with no hope of recovery. However, in the US, CPR quickly became a standard treatment for all patients who arrested, although it was a “rite of passage to death for most.”⁷² However, in the 1960’s,

⁶⁹ Leng and Sy “Advance Medical Directives in Singapore” (1997) 5 *Medical Law Review* 63 at 72.

⁷⁰ *Ibid* at 73.

⁷¹ See generally Madden *Medicine, Ethics & the Law* (Tottel Publishing 2002) at paragraphs 11.70-11.83; Mills *Clinical Practice and the Law* (2nd ed Tottel Publishing 2007) at paragraphs 12.29-12.30; Robinson and O’Neill “Communication and Documentation of Do-Not-Resuscitate Orders in an Irish Teaching Hospital” (2005) 11(2) *Medico-Legal Journal of Ireland* 60; Sheikh “Older People: Consent, Do Not Resuscitate Orders and Medical Research” in O’Dell (ed) *Older People in Modern Ireland: Essays on Law and Policy* (First Law 2001) 213. It has been proposed that the term “DNR” should be replaced with the term “AND” (allow natural death), as it positively describes the contents of care, rather than focusing on the negative “do-not” directives. It is argued that DNR are “threatening” words which evoke a perception of coldness and cruelty: Venneman, Narnor-Harris and Hamilton “‘Allow Natural Death’ Versus ‘Do Not Resuscitate’: Three Words that Can Change a Life” (2008) 34 *Journal of Medical Ethics* 2.

⁷² Sorum “Limiting Cardiopulmonary Resuscitation” (1994) 57 *Alberta Law Review* 617 at 617-618.

the doctrine of informed consent became more widely recognised, allowing for increased patient autonomy and a decline in unilateral decision-making by physicians. This increase in autonomy resulted in the appearance of DNR orders. By 1986, most hospitals had implemented DNR orders, and in 1987, New York State became the first state to pass DNR legislation.⁷³

(ii) Ireland

1.41 In a 2003 study it was reported that 96% of life-sustaining treatment withheld in the Mater Hospital in Dublin involved CPR.⁷⁴ In a separate study, also conducted in 2003, physicians were asked if they thought any patient group was more likely to be the subject of a DNR order. In response, the most common groups mentioned were “terminally ill”, “elderly” and “terminally ill and elderly.”⁷⁵ Despite such findings, there are no medical guidelines, and there is no legislation or judicial precedent to guide medical practitioners and patients in this area of medicine. This medico-legal vacuum has resulted in a “high level of dissatisfaction, confusion and varying practices among Irish consultant physicians regarding resuscitation decisions.”⁷⁶

(iii) England and Wales

1.42 The legality of withholding CPR was first discussed in England in *Re R (Adult: Medical Treatment)*.⁷⁷ R was a 23-year old patient born with serious brain damage and Cerebral Palsy. He had developed severe epilepsy at 8 months old, had minimum cognitive awareness, and was thought to be deaf, blind and incontinent. He had to be fed through a syringe, and was hospitalised five times in the year leading to the making of the DNR order. His consultant

⁷³ American Hospital Association *Effective DNR Policies: Development, Revision and Implementation* (1990).

⁷⁴ Collins “End of Life in ICU – Care of the Dying or ‘Pulling the Plug’?” (2006) 99(4) *Irish Medical Journal* 112.

⁷⁵ 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. Although the study was conducted in 2003, the results were not published until 2006.

⁷⁶ 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 210.

⁷⁷ [1996] 2 FLR 99.

and parents agreed that if R were to experience another life-threatening condition, it would be in his best interests that CPR should not be given. An application was brought by way of judicial review by members of R's residential home to quash the DNR decision. The Family Division of the English High Court held that it would be lawful to withhold CPR, basing its decision on a number of factors. First, the chances of a successful CPR on R by residential home staff, without medical staff present, would be "almost nil." Moreover, if CPR were attempted, R might not only suffer further brain damage, but due to the fragility of his body, excessive pressure might also lead to damage to his ribs or more serious complications. Therefore, the court held that it would be lawful for the doctor to withhold CPR, given the likely futility of attempts to resuscitate R successfully. The Court noted that:

"...there is no question of the court being asked to approve a course of treatment aimed at terminating life or accelerating death. The court is concerned with circumstances in which steps should not be taken to prolong life....The principle of law to be applied in this case is that of the 'best interests of the patient'."⁷⁸

1.43 In 2002, the British Medical Association and the Royal College of Nursing drafted guidelines to deal with DNR decisions.⁷⁹ They observe that:

"Cardiopulmonary resuscitation can be attempted on any person whose cardiac or respiratory functions cease. Failure of these actions is part of dying and thus CPR can theoretically be attempted on every individual prior to death. But because for every person there comes a time when death is inevitable, it is essential to identify patients for whom cardiopulmonary arrest represents a terminal event in their illness and in whom attempted CPR is inappropriate. It is also essential to identify those patients who do not want CPR to be attempted and who competently refuse it."⁸⁰

1.44 The guidelines consider that it is appropriate to make a DNR order in the following circumstances:

- "Where attempting CPR will not restart the patient's heart and breathing;

⁷⁸ [1996] 2 FLR 99 at 107.

⁷⁹ British Medical Association and Royal College of Nursing *Decisions Relating to Cardiopulmonary Resuscitation: A Joint Statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing* (2002).

⁸⁰ *Ibid* at 5.

- Where there is no benefit in restarting the patient's heart and breathing;
- Where the expected benefit is outweighed by the burdens.”⁸¹

1.45 It is noted that, ideally, decisions regarding CPR should be made and discussed in advance as part of overall care planning. They specifically state that an advance decision refusing CPR should only be made after the appropriate consultation and consideration of all relevant aspects of the patient's condition, which include:

- “the likely clinical outcome, including the likelihood of successfully restarting the patient's heart and breathing, and the overall benefit achieved from a successful resuscitation;
- the patient's known or ascertainable wishes; and
- the patient's human rights, including the right to life and the right to be free from degrading treatment.”⁸²

1.46 In light of this, the Commission has provisionally concluded that the status of DNR orders requires clarification in Irish law and invites submissions on them

1.47 *The Commission invites submissions on the status of “Do Not Resuscitate” (DNR) orders.*

(4) What forms of treatment cannot be refused in an advance care directive

(a) Basic care

1.48 The right to refuse treatment has limitations. The Commission agrees with the Law Commission for England and Wales that public policy demands that:

“... an advance refusal of treatment should not preclude the provision of ‘basic care’, namely care to maintain bodily cleanliness and to

⁸¹ British Medical Association and Royal College of Nursing *Decisions Relating to Cardiopulmonary Resuscitation: A Joint Statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing* (2002) at 11-12.

⁸² British Medical Association and Royal College of Nursing *Decisions Relating to Cardiopulmonary Resuscitation: A Joint Statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing* (2002) at 7-8.

alleviate severe pain, as well as the provision of direct oral nutrition and hydration.”⁸³

1.49 This limitation is based on a number of public policy considerations. First, if patients could make an anticipatory decision to refuse even the most basic steps to ensure comfort and cleanliness, there would be an adverse effect on staff and other patients.⁸⁴ Allied to this consideration is that it is “bad for society as a whole to tolerate the negative effects of individuals’ choices in respect of unrelieved pain or neglect.”⁸⁵ Third, a doctor would have to effectively abandon his patient were he required to refrain from treating that patient.⁸⁶ The Law Commission for England and Wales concluded that it did not regard this limitation as a “significant infringement of the patient’s right of self-determination” and in any event, did not expect many people to make a directive refusing basic care.⁸⁷

1.50 Although the English *Mental Capacity Act 2005* does not explicitly provide for the exclusion of ‘basic care’ in advance decisions, the *Code of Practice* is in line with the English Law Commission’s recommendations:

“An advance decision cannot refuse actions that are needed to keep a person comfortable (sometimes called basic or essential care). Examples include warmth, shelter, actions to keep a person clean and the offer of food and water by mouth.”⁸⁸

1.51 The Law Reform Commission of Hong Kong recommended that basic care and also palliative care should always be provided. It declined to provide a definition of what might constitute basic or palliative care, preferring to

⁸³ The Law Commission of England and Wales *Report on Mental Incapacity* (No 231 1995) at paragraph 5.34. The Commission replaced reference to “spoon-feeding” with reference to direct oral feeding, to cater for the administration of nutrition and hydration by syringe or cup.

⁸⁴ *Ibid* at paragraph 5.34. See Mills *Clinical Practice and the Law* 2nd ed., (Tottel, 2007) at paragraph 12.33.

⁸⁵ English, Mussell, Sheather and Sommerville “Autonomy and Its Limits: What Place for the Public Good?” in McLean (ed) *First Do No Harm* (Ashgate 2006) 117 at 118.

⁸⁶ Grubb “United Kingdom” [1993] 1(1) *Medical Law Review* 84 at 85.

⁸⁷ The Law Commission of England and Wales *Report on Mental Incapacity* (No 231 1995) at paragraph 5.34.

⁸⁸ *Mental Capacity Act 2005 - Code of Practice* at paragraph 9.28. Section 5 of the *Mental Capacity Act 2005* allows healthcare professionals to carry out these actions in the best interests of a person who lacks capacity to consent.

leave the matter to be decided by the medical profession in accordance with the medical practice prevailing at the time when a person's advance directive is to be executed. It suggested that the following wording should be used in the model advance directive form:

"Save for basic and palliative care, I do not consent to receive any life-sustaining treatment. Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care."⁸⁹

1.52 *The Commission provisionally recommends that an advance care directive cannot refuse actions concerning basic care.*

(b) Enforced treatment

1.53 Under the English *Mental Capacity Act 2005*, an advance decision will not operate to prevent treatment where consent is not necessary,⁹⁰ for example, where enforced treatment is provided to civilly confined patients under Part IV of the *Mental Health Act 1983* as amended by section 12 of the *Mental Health Act 2007*.

(c) Refusing life-sustaining treatment during pregnancy

1.54 A question arises where a woman refuses life-sustaining treatment during the course of a pregnancy. The Scottish Law Commission has argued that a terminally ill woman ought to be kept alive for "longer than strictly necessary" if there is a reasonable chance of thereby saving her unborn child.⁹¹ The Law Commission for England and Wales considered the issue in its 1995 *Report on Mental Incapacity* and recommended a statutory presumption that advance refusals of treatment would not apply if the viability of a foetus were at risk.⁹² The English *Mental Capacity Act 2005* chose not to incorporate a presumption to this effect. However, the Code of Practice made under the 2005 Act does advise healthcare professionals to consider whether there have been changes in the patient's personal life which were not anticipated when they made the advance decision that might affect the validity of the advance decision. It specifically cites pregnancy as an example of such a change.⁹³

⁸⁹ Law Reform Commission of Hong Kong *Report on Substitute Decision-Making and Advance Directives in Relation to Medical Treatment* (2006) at 169.

⁹⁰ Section 28 of the *Mental Capacity Act 2005*.

⁹¹ Scottish Law Commission *Discussion Paper on Mentally Disabled Adults – Legal Arrangements for Managing their Welfare and Finances* (No 94 1991) at paragraph 5.111.

⁹² The Law Commission for England and Wales *Report on Mental Incapacity* (No 231 1995) at paragraph 5.26

⁹³ *Mental Capacity Act 2005 - Code of Practice* at paragraph 9.43.

However the refusal of life-sustaining treatment during pregnancy is outside the scope of this paper. This matter would be affected by Article 40.3.3° of the Constitution of Ireland.

F Healthcare Proxy

(1) Instructional directives

1.55 An instructional directive is a document by which a person specifies his or her wishes concerning future treatment. There are a significant number of drawbacks to this form of advance care directive. First, an instructional directive is often a “standard, fill-in-the-blanks form” and therefore lacks flexibility.⁹⁴ Secondly, the information provided may not be clinically relevant. For example, some directives use vague statements such as “take no heroic measures” or “continue treatment only if the benefits outweigh the burdens.”⁹⁵ Conversely, instructional directives that outline specific interventions may fail to instruct a physician because “not all treatment situations fit neatly into one of the specific scenarios.”⁹⁶ Third, people frequently change their minds. As Clough has noted, “when placed in the midst of an illness, what once was unthinkable may become acceptable.”⁹⁷ Fourth, medical science may advance considerably in the period between the making of the advance care directive and the medical situation provided for arising in practice.⁹⁸

(2) Appointing a person to carry out advance care directives

1.56 Patients may wish to designate a person (commonly known as a proxy) who can represent them in a situation of future incompetence and who has the authority to give or to withhold consent to medical interventions on their behalf. The central advantage is that the proxy can “step into the shoes of the patient and make decisions in the light of the current medical situation and the advice of the attending physician” whereas an instructional directive “may not

⁹⁴ Dunlap “Mental Health Advance Directives: Having One’s Say?” (2000-2001) 89 *Kentucky Law Journal* 327 at 347.

⁹⁵ In a study by Teno et al, only 22 of 688 advance care directives written by terminally ill patients contained instructions explicit enough to guide medical care: Teno et al “Do Advance Directives Provide Instructions that Direct Care?” (1997) 45 *Journal of the American Geriatric Society* 508.

⁹⁶ Clough “A Critique of Advance Directives and Advance Directives Legislation” (2006) 11 *Appeal: Review of Current Law and Law Reform* 16 at 29.

⁹⁷ *Ibid* at 30.

⁹⁸ Law Reform Commission *Consultation Paper on Vulnerable Adults and the Law: Capacity* (LRC CP 37-2005) at paragraph 7.64.

address the situation or may be so ambiguous as to create more confusion than clarity about what the patient would want.”⁹⁹ However there are difficulties associated with being an ‘ideal proxy’. For proxies who are emotionally connected with the patient, such as relatives and close friends, personal considerations can be hard to disentangle “whether the proxy is unable to face the death of a loved one, or anxious to end the overwhelming financial burden of caring for the patient, or in moral disagreement with the patient’s considerations.”¹⁰⁰ The difficulty for previously disinterested proxies is that decision-making regarding life-sustaining care is inherently very burdensome which in itself may influence how the proxy makes suitable judgments for the patient.¹⁰¹

(a) Powers of attorney

(i) Commission’s Recommendations and Government Proposals

1.57 An Enduring Power of Attorney (EPA) is a legal mechanism established by the *Powers of Attorney Act 1996* for granting certain decision-making powers to a nominated attorney in the event that the person loses capacity. At present, EPAs can only give attorneys the power to make decisions about property, financial and business affairs, and personal care decisions on behalf of the donor. As currently defined, personal care decisions cover matters such as where the donor is to live and day-to-day matters, but do not encompass healthcare decisions. In the aftermath of *Re a Ward of Court (No 2)*¹⁰² calls were made for legislation that would make it possible for patients, by means of a power of attorney, to empower relatives to make treatment decisions on their behalf in the event of incapacity.¹⁰³ The Commission has recommended in its 2006 Report on *Vulnerable Adults and the Law* that an EPA should be capable of permitting an attorney to make certain healthcare decisions on behalf of the donor where the donor lacks capacity to make the

⁹⁹ Capron “Advance Directives” in Kuhse and Singer (eds) *A Companion to Bioethics* (Blackwell Publishing 1998) 261, at 266. See also Woollard “The Appointment of Medical Treatment Attorneys: Some Lessons From Australia” (1998) 6 *Medical Law Review* 297.

¹⁰⁰ Emanuel “Advance Directives: What Have We Learned So Far?” in Emanuel (advisory ed) *Advance Directives: Expectations, Experience and Future Practice* (1993) 4(1) *The Journal of Clinical Ethics* 8 at 10.

¹⁰¹ *Ibid.*

¹⁰² [1996] 2 IR 79, discussed in Chapter 2, below.

¹⁰³ Harrington “Constitutional Law – Withdrawal of Treatment from an Incompetent Patient” (1995) 17 DULJ 120 at 135.

decision.¹⁰⁴ The Commission believes that this would serve two purposes: first, it would ensure a congruence of approach in decision-making structures;¹⁰⁵ and second, it would avoid a decision-making vacuum occurring in the important area of healthcare. The Commission welcomes the publication in September 2008 of the Government's *Scheme of Mental Capacity Bill 2008*¹⁰⁶ which is largely based on the Commission's 2006 Report. The Commission notes that Head 48 of the Scheme proposes to allow an attorney to make health care decisions. The Commission very much looks forward to the publication of the Government's Bill based on the Scheme, which is scheduled for 2009.

(ii) Lasting powers of attorney

1.58 The English *Mental Capacity Act 2005* provides a statutory framework for powers of attorney, now called 'lasting' powers of attorney (LPAs).¹⁰⁷ The welfare decisions which an attorney will be permitted to make include decisions on the carrying out or continuation of medical treatment.¹⁰⁸ However, neither an LPA nor an advance decision can require a treatment provider to offer a specific treatment. The views of the donor will however, be taken into account in a best interests determination.¹⁰⁹ Section 11(8) of the 2005 Act provides that a donee has the power to refuse life-sustaining treatment on the donor's behalf, but only if the LPA says so expressly.

1.59 An LPA that covers matters relating to medical consent can be distinguished from an advance decision:

"The [LPA] appoints someone to make treatment decisions, subject to the best interests criteria and such restrictions as are contained in the instrument itself. The advance decision makes the decision: there

¹⁰⁴ Law Reform Commission *Report on Vulnerable Adults and the Law* (LRC 82-2006) at paragraph 8.43.

¹⁰⁵ This range of decisions would be on a par with those which could be made by personal guardians appointed under the proposed mental capacity and guardianship legislation. See *Report on Vulnerable Adults and the Law* (LRC 82-2006) at paragraph 6.50 ff.

¹⁰⁶ Available at www.justice.ie.

¹⁰⁷ Sections 9-14 of the *Mental Capacity Act 2005*. See Martin "Powers of Attorney – Peace of Mind or Out of Control" (2008) *Conveyancer and Property Lawyer* 11.

¹⁰⁸ Section 11(7)(c) of the *Mental Capacity Act 2005*.

¹⁰⁹ Section 9(4) of the *Mental Capacity Act 2005*.

is at least in theory no routine assessment of the wisdom or desirability of the decision.”¹¹⁰

1.60 Where an advance decision is valid and applicable, the best interests principle does not apply. This is to reflect the fact that the advance decision is an autonomous choice made by a competent adult. The Code of Practice made under the English 2005 Act notes that healthcare professionals must follow a valid and applicable advance decision, even if they think it goes against a person’s best interests.¹¹¹ A further distinction between an LPA and an advance decision can be identified:

“The inclusion of medical decision-making in an [LPA] will be appropriate to deal with unforeseen maladies occurring after the onset of incapacity. The advance decision will be appropriate when [the maker] has firm and fixed views about refusal of a definable treatment, set of treatments, or course of treatment in definable future situations.”¹¹²

1.61 LPAs are subject to advance decisions to refuse treatment. Section 25(7) of the 2005 Act states:

“the existence of any lasting power of attorney...does not prevent the advance decision from being regarded as valid and applicable.”

However, section 25(2)(b) states:

“an advance decision is not valid if [a person] has, under a lasting power of attorney created after the advance decision was made, conferred authority on the donee...to give or refuse consent to the treatment to which the advance decision relates.”

(3) Combination directives

1.62 A combination of an instructional directive with an Enduring Power of Attorney may be the most effective way to ensure that an individual’s wishes are respected. The drawback of each type of document is counterbalanced by the presence of the other. Combination advance directives can thus serve as

¹¹⁰ Bartlett *Blackstone’s Guide to the Mental Capacity Act 2005* (Oxford University Press 2005) at paragraph 2.113.

¹¹¹ *Mental Capacity Act 2005 – Code of Practice* at paragraph 9.36.

¹¹² Bartlett *Blackstone’s Guide to the Mental Capacity Act 2005* (Oxford University Press 2005) at paragraph 2.113.

“tools that facilitate making difficult decisions in uncertain times, not as static dogmatically binding documents.”¹¹³

(4) Healthcare Proxy

1.63 As the Commission has previously pointed out, there is a decision-making vacuum in the area of healthcare concerning incompetent patients.¹¹⁴ The Commission has thus recommended that the *Enduring Power of Attorney Act 1996* be extended to include healthcare decisions. The Commission recognises the person appointed to take care of financial matters may not be the same person appointed to make healthcare decisions. There is the added problem that there are number of formalities required to establish an Enduring Power of Attorney. However, such formalities may not be appropriate to establish an advance care directive.¹¹⁵ The Commission is aware, of course, and discusses this in detail in this Consultation Paper, that advance care directives can also take the form of a verbal statement, especially in reply to a series of questions when a person is suddenly admitted to hospital and they do not have a written advance directive to hand. In that respect, changes to the law on powers of attorney will not deal with all circumstances in which advance care directives may arise.

1.64 In this respect, the Commission has concluded that a more general legal framework is also needed in which a healthcare proxy could be appointed in the context of advance care directives.

1.65 *The Commission provisionally recommends that a healthcare proxy may be appointed in an advance care directive. The functions of a healthcare proxy should include:*

- *Ensuring that the wishes as expressed by the author of the advance care directive are followed; and*
- *Consultation with the medical professional if there is any ambiguity in the advance care directive.*

¹¹³ Kirscher “When Written Advance Directives Are Not Enough” (2005) 21(1) *Clinics in Geriatric Medicine* 193 at 195.

¹¹⁴ Law Reform Commission *Report on Vulnerable Adults and the Law* (LRC 82-2006) at paragraph 4.31.

¹¹⁵ See Chapter 4 generally.

CHAPTER 2 LEGAL BASIS FOR THE RECOGNITION OF ADVANCE CARE DIRECTIVES

A Introduction

2.01 This Chapter explores the legal basis for recognising advance care directives. In Part B, the Commission discusses how the constitutional right to refuse treatment in Irish law provides a framework for advance care directives. In Part C, the Commission examines US judicial and legislative developments and whether the ‘living will’ has gained widespread acceptance. In Part D, the Commission discusses the recognition of advance care directives at common law in England and Wales, and the road to legislative reform, culminating in the English *Mental Capacity Act 2005*. In Part E, the Commission explores Australian laws on advance care directives, and considers whether the recognition of both common law and statutory advance care directives, resulting in a two-tier system, would result in unnecessary uncertainty. In Part F, the Commission discusses the 2006 Hong Kong report on Advance Care Directives. In Part G, the Commission notes that the right to refuse treatment can be located in a number of articles contained in the European Convention on Human Rights, and that the European Convention on Human Rights and Biomedicine contains a specific article on “previously expressed wishes”. In Part H, the Commission notes the recommendation of the Manitoba Law Reform Commission that fundamental principles and policies concerning advance care directives should be embodied in a statement of the College of Physicians and Surgeons of Manitoba, as opposed to legislation. In Part I, the Commission sets out its view that there is a need for a general legal framework for advance care directives. In Part J, the Commission discusses advance care directives that refuse treatment on religious grounds, and the recent judgment of Laffoy J in April 2008 in the *K* case.

B The Irish legal position

(1) *Constitutional right to refuse treatment*

2.02 In 1986, Costello J, writing extra-judicially, suggested that the right of the terminally ill patient to forego life-sustaining treatment is compatible with the provisions of the Constitution:

“...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...in 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

2.03 In the 1996 judgment of *Re a Ward of Court (No 2)*,² Costello J’s article was cited with approval by the Supreme Court.³ O’Flaherty J stated:

“there is an absolute right in a competent person to refuse medical treatment even if it leads to death.”⁴

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.”⁵ 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.”⁶

2.04 As a result, the right to refuse treatment “does not sit easily with the traditional ethos of the medical profession, which was paternalistically based on

¹ Costello “The Terminally Ill – The Law’s Concerns” (1986) 21 *Irish Jurist* 35 at 42.

² [1996] 2 IR 79

³ *Ibid* at 125 per Hamilton CJ.

⁴ *Ibid* at 129.

⁵ *Ibid*.

⁶ *Ibid* at 156. It is interesting to note that the following italicised text in the unreported approved judgment of Denham J in *Re a Ward of Court (No 2)* 27 July 1994 at p. 24 of the judgment 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.”

the principle that ‘the doctor knows best’.”⁷ Thus refusal of consent is seen “not as an assertion of will, but rather as a symptom of unsoundness of mind.”⁸

2.05 However, the right to refuse medical treatment is not absolute. Costello J first suggested, extra-judicially, that the claims of the common good might justify restrictions on the exercise of a constitutionally protected right to refuse medical treatment in the case of contagious diseases.⁹ Ten years later, Denham J added that the right was also not absolute in medical emergencies where patients are unable to communicate.¹⁰ Furthermore, Casey has suggested that a pregnant woman’s right to refuse medical treatment might be restricted where the consequence of such refusal would be the death of the unborn child.¹¹

(2) Re a Ward of Court (No 2)

2.06 In 1995, Tomkin and Hanafin proposed that the Irish legislature adopt the recommendation of Law Commission of England and Wales in its *Report on Mental Capacity* (which formed the background to the English *Mental Capacity Act 2005*) that the law in relation to advance directives be placed on a statutory footing.¹² They argued that since the Commission’s recommendation was based on a similar common law tradition, legislation could be easily accommodated within an Irish statutory framework. They concluded, however, that a major obstacle could be Ireland’s “antipathy to pioneering social legislation which aims to afford greater protection to individual autonomy over cultural conventions.”¹³

2.07 Whilst the Oireachtas did not respond to their calls, there is an indirect reference to advance care directives in *Re a Ward of Court (No 2)*.¹⁴ A number of Irish commentators have argued that an advance care directive

⁷ Madden *Medicine, Ethics & the Law* (Tottel Publishing 2002) at paragraph 9.134.

⁸ Kennedy *Treat Me Right: Essays in Medical Law and Ethics* (1991) at 337 cited in Madden *ibid* at paragraph 9.136.

⁹ Costello “The Terminally Ill – The Law’s Concerns” (1986) 21 *Irish Jurist* 35 at 42.

¹⁰ *In re a Ward of Court (withholding medical treatment) (No 2)* [1996] 2 IR 79 at 156. The dictum of Denham J in this regard was cited by Hardiman J in *North Western Health Board v HW* [2001] 3 IR 622 at 750-151.

¹¹ Casey *Constitutional Law in Ireland* (3rd ed Round Hall Sweet & Maxwell 2000) at 400.

¹² Tomkin and Hanafin “Medical Treatment at Life’s End: The Need for Legislation” (1995) *Medico-Legal Journal of Ireland* 3 at 9.

¹³ *Ibid.*

¹⁴ [1996] 2 IR 79 at 133.

would be respected by an Irish court on the basis of *Ward*. First, Campbell cites an *obiter* statement of O’Flaherty J, who when considering the apposite test to apply in the case, 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 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.”¹⁵

2.08 She therefore argues that O’Flaherty J’s dictum suggests that if an individual had the foresight to express his wishes in an advance directive, an Irish court would uphold its validity.¹⁶ Furthermore, Madden propounds 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.¹⁷ Mills, having proclaimed *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.”¹⁸

(3) Commission’s Recommendations

2.09 In its 2006 *Report on Vulnerable Adults and the Law* the Commission recommended the establishment of a Guardianship Board to determine the capacity of the individual.¹⁹ The board would have the power to appoint a personal guardian who has the power to make day-to-day healthcare decisions.²⁰ The Commission also recommended that certain major healthcare

¹⁵ [1996] 2 IR 79 at 133.

¹⁶ Campbell “The Case for Living Wills in Ireland” (2006) 12(1) *Medico-Legal Journal of Ireland* 2 at 6.

¹⁷ Madden *Medicine, Ethics & the Law* (Tottel Publishing 2002) at paragraph 11.57.

¹⁸ Mills *Clinical Practice and the Law* (2nd ed Tottel Publishing 2007) at paragraph 329.

¹⁹ *Report on Vulnerable Adults and the Law* (LRC 83-2006) at paragraph 6.40. The Commission notes that the Government’s *Scheme of Mental Capacity Bill 2008*, published in September 2008, proposes that the Circuit Court would perform the functions envisaged by the Commission for the Guardianship Board.

²⁰ *Report on Vulnerable Adults and the Law* (LRC 83-2006) at paragraph 6.51.

treatment, such as the withdrawal of artificial life-sustaining healthcare treatment, should be reserved for the High Court.²¹

2.10 Recognising that there are many healthcare treatments that would not be described as major or minor, the Commission recommended that the proposed mental capacity legislation empowers the Minister for Health to appoint a Working Group on Capacity to Make Healthcare Decisions.²² This Working Group would formulate a code of practice which would include guidelines on what type of healthcare decisions would require an application to the court.²³

(4) Irish Medical Council

2.11 The Irish Medical Council's most recent edition of *A Guide to Ethical Conduct and Behaviour* does not contain a specific reference to advance care directives. The guide provides however, that a competent adult patient has the right to refuse treatment. It also advises that while the decision must be respected, the assessment of competence and the discussion of consent should be carried out in conjunction with a senior colleague.²⁴ In 2007, the Irish Medical Council produced a discussion document on advance directives. It states that:

“Where a competent adult patient makes a specific and informed decision to refuse future medical treatment in the event of his/her incapacity, this decision should be respected.

Patients should be encouraged to nominate a trusted person to interpret their wishes in the event of any ambiguity. If there is uncertainty regarding the patient's competence at the time of making the directive, or its continued applicability in the present circumstances, doctors should err on the side of caution and maintain

²¹ *Report on Vulnerable Adults and the Law* (LRC 83-2006) at paragraph 6.72. The Government's *Scheme of Mental Capacity Bill 2008* proposes to implement this recommendation.

²² *Report on Vulnerable Adults and the Law* (LRC 83-2006) at paragraph 3.34.

²³ *Ibid* at paragraph 3.35. The Government's *Scheme of Mental Capacity Bill 2008* proposes that the Office of Public Guardian, which the Commission recommended in its 2006 Report should be established, will formulate this Code of Practice.

²⁴ Irish Medical Council *A Guide to Ethical Conduct and Behaviour* (6th ed 2004) at paragraph 17.1.

the status quo pending a judicial determination of the issue if necessary.”²⁵

2.12 The Women’s Health Council has noted that the issue of advance care directives is a key ethical challenge in contemporary medical practice and should be included in the next edition of the Irish Medical Council’s ethical guidelines.²⁶

(5) Next of kin

2.13 In Ireland, where an adult does not have the capacity to make a decision to consent to or refuse treatment, it is common medical practice to require that person’s next of kin to sign a consent form in relation to the treatment. The Irish Medical Council advises its members that:

“For the seriously ill patient who is unable to communicate or understand, it is desirable that the doctor discusses management with the next of kin or the legal guardians prior to the doctor reaching a decision particularly about the use or non-use of treatments which will not contribute to recovery from the primary illness.”²⁷

2.14 However, one of the reasons for the emergence of advance care directives in society is the growing recognition that there is in fact no legal basis for this practice. Competent patients have the right to refuse treatment. The fact that they have become incompetent does not mean that their right to refuse treatment can be ignored. McMahon and Binchy observe that:

“Principles of bodily integrity and autonomy should be given due weight; paternalism, outside the context of judicial exercise of its *parens patriae* jurisdiction, should not be let to run rampant, merely because the object of the benevolent intervention lacks the capacity to refuse it.”²⁸

2.15 Indeed, the Commission acknowledged in its *Consultation Paper on Law and the Elderly* in 2003 that:

²⁵ Irish Medical Council *Advance Directives* (2007) at 3. Available at www.medicalcouncil.ie/news/discussionarticle.asp?NID=158&T=N.

²⁶ The Women’s Health Council *Submission to the Medical Council on ‘A Guide to Ethical Conduct and Behaviour’* (September 2007) at 7. Available at www.whc.ie/documents/26_Submission_Ethical.pdf.

²⁷ Irish Medical Council *A Guide to Ethical Conduct and Behaviour* at paragraph 22.1.

²⁸ McMahon and Binchy *Law of Torts* (3rd ed Butterworths 2000) at paragraph 22.73.

“the law on consent to medical treatment may need to be addressed because of the widespread false belief that family members and carers may make valid decisions on behalf of people who do not have legal capacity.”²⁹

2.16 In *Re a Ward of Court (No 2)*³⁰ both the High Court and Supreme Court judgments referred to the importance of doctors consulting with the families of patients in a persistent vegetative state before deciding on the course of treatment. Importantly, however, the family did not have the power, pursuant to its imprescriptible rights under Article 41 of the Constitution of Ireland, to make the final decision. The case concerned a Ward of Court, and therefore the jurisdiction to make the decision to withdraw artificial nutrition and hydration lay with the court and not the family. The only rights at issue were the personal rights of the ward, and not the institutional rights of the family.³¹ Unfortunately, the court did not pronounce on the position of adults who lack capacity, but have not been made a Ward of Court.

2.17 In its Consultation Paper on *Vulnerable Adults and the Law: Capacity*, the Commission considered whether a medical practitioner would be liable in professional negligence for accepting the signature of a next of kin on a consent form.³² In *Daniels v Heskin*,³³ it was held that a medical practitioner cannot be held negligent if he follows the general and approved practice in the situation with which he is faced. Walsh J qualified that proposition however, in *O'Donovan v Cork County Council*.³⁴

“If there is a common practice which has inherent defects which ought to be obvious to any person giving the matter due consideration, the fact that it is shown to have been widely and generally adopted over a period of time does not make the practice any the less negligent. Neglect of duty does not cease by repetition of neglect of duty.”³⁵

²⁹ Law Reform Commission *Consultation Paper on Law and the Elderly* (LRC CP 23-2003) at paragraph 1.23.

³⁰ [1996] 2 IR 79.

³¹ *Ibid* at 163-164 per Denham J.

³² Law Reform Commission *Consultation Paper on Vulnerable Adults and the Law: Capacity* (LRC CP 37-2005) at paragraph 7.37.

³³ [1954] IR 73.

³⁴ [1967] IR 173

³⁵ *Ibid* at 193.

The Commission therefore concluded that it would not be a complete answer for a medical practitioner to give evidence of the widely established nature of the practice of next of kin signing consent forms.

2.18 However, it has been acknowledged that there are advantages associated with allowing the next of kin to make such decisions. For example, it has been argued that:

“what the practice does have to recommend it is a practical, socially accepted tradition of allowing those most concerned with the welfare of the patient to make treatment choices for him or her during the final days and weeks of a terminal illness, or where a hopeless, vegetative existence is involved. The practice of allowing family and physicians to decide these questions is now so firmly rooted in tradition and social acceptance, that only in rare instances of reported abuse will it be challenged.”³⁶

2.19 Furthermore, the practice may “reveal the personal circumstances of the patient, the sorts of choices which they might have made if they had been in a position to do so and whether the patient has in fact made an anticipatory choice.”³⁷ The argument has also been constructed that recourse to the courts may “increase the likelihood that the values of medical professionals or of the court representing some kind of social consensus or average as opposed to those of the patient will be determinative of the case.”³⁸

2.20 On the other hand, however, as Costello warns extra-judicially, it can “no longer be assumed that husbands and wives inevitably share an identity of interest. Moreover, it is no longer an easy matter to define a family and to rely on the advice of visitors at the bedside is no longer adequate.”³⁹

³⁶ Meyers “Letting Doctor and Patient Decide: The Wisdom of Scots Law” in *Comparative and Historical Essays in Scots Law* (Butterworths 1992) at 101.

³⁷ Morgan “Odysseus and the Binding Directive: Only a Cautionary Tale?” (1994) 14 *Legal Studies* 411 at 428.

³⁸ Harrington “Withdrawal of Treatment from an Incompetent Patient” (1995) 17 *Dublin University Law Journal* 120 at 125.

³⁹ Costello “The Terminally Ill – The Law’s Concerns” (1986) 21 *Irish Jurist* 35 at 46.

C United States of America

(1) *Re Quinlan*

2.21 The 1976 New Jersey Supreme Court decision in *Re Quinlan*⁴⁰ concerned the plight of a Karen Ann Quinlan, a 22 year-old woman who was in a persistent vegetative state. Her physicians refused to turn off her respirator, fearing that to terminate treatment would attract the imposition of criminal liability and would be contrary to medical practice and standards. Her father sought a court order empowering him to authorise the discontinuance of “all extraordinary medical treatment”, arguing that that was what his daughter would have wanted. The Supreme Court held that the constitutional right to privacy could be extended to the patient who refuses life-sustaining treatment. It concluded that the State’s 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 we believe Karen’s choice, if she were competent to make it, would be vindicated by the law.”⁴¹

Although there was no advance directive in *Quinlan*, the case highlighted the horrific plight of Ms Quinlan and her family, and galvanised public interest in “moving living wills from their shadowy existence as hortatory statements to officially recognised instructions.”⁴²

(2) *Legislative developments*

2.22 Within months of *Re Quinlan*, the first advance care directive legislation was enacted in 1976 by the Californian legislature,⁴³ with other states quickly following suit. This first generation of ‘living will’ statutes was concerned only with the refusal of life-sustaining procedures in the event of ‘terminal illness’ or ‘imminent death’. However, such statutes that, for example, required that death be ‘imminent’ or occur within a ‘short time’, were criticised as substituting a time measure for the more appropriate question regarding the futility of medical treatment.⁴⁴ Given the limited application of such statutes, a

⁴⁰ (1976) 355 A.2d 647.

⁴¹ (1976) 355 A.2d 647.

⁴² Capron “Advance Directives” in Kuhse and Singer (ed) *A Companion to Bioethics* (Blackwell Publishing 1998) at 264.

⁴³ *Natural Death Act 1976*.

⁴⁴ Gelfand “Living Will Statutes: The First Decade” (1987) *Wisconsin Law Review* 737, at 744.

second generation of statutes emerged, permitting the creation of durable powers of attorney which were specifically concerned with health care decisions.⁴⁵ Subsequently, a third generation of hybrid statutes developed, which combined provisions related to living wills with the option of appointing a proxy decision-maker. A fourth generation of advance care directive legislation has recently emerged, which vests power in the patient's family members where the patient has not made an advance directive.⁴⁶

2.23 In 1985 the *Uniform Rights of the Terminally Ill Act* was drafted by the US Uniform Law Commissioners in an attempt to make state laws uniform in purpose and form. However, the success of this legislation appeared to have a limited effect: in a 1989 report it was noted that only 9% of Americans had executed advance directives.⁴⁷

(3) Cruzan v Director, Missouri Department of Health

2.24 The Supreme Court decision in *Cruzan v Director, Missouri Department of Health*⁴⁸ in 1990 served as a powerful catalyst for legislative reform. There, the family of Nancy Cruzan, who was in a persistent vegetative state, sought 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 Supreme Court held that competent persons have a "constitutionally protected liberty interest in refusing unwanted medical treatment."⁴⁹ A flurry of legislative activity took place in the United States as a result of *Cruzan*. First, existing legislation was amended, as the Supreme Court had not drawn a distinction between the withdrawal of artificial nutrition and hydration and other medical treatment.⁵⁰ Second, and more importantly, the Supreme Court held that states could insist on "clear and convincing evidence" of a patient's wishes before permitting hospitals to withdraw life support. The Court noted that written instructions - such as those provided in a living will - are persuasive evidence of an individual's "prior

⁴⁵ The first and best-known example was again in California: the *Durable Power of Attorney Health Care Act 1983*.

⁴⁶ Indiana is an example of a state which has enacted such legislation.

⁴⁷ Emanuel and Emanuel "The Medical Care Directive: A New Comprehensive Care Document" (1989) 261 *Journal of American Medical Association* 3288 cited by Brennan J (dissenting) in *Cruzan v Missouri Department of Health* (1990) 110 S Ct 2841 at 2875 n.21.

⁴⁸ (1990) 497 US 261.

⁴⁹ *Ibid* at 278.

⁵⁰ Kennedy and Grubb *Medical Law* (3rd ed Butterworths 2000) at 2047.

expressed wishes” regarding medical treatment. However, the “informal, casual statements her friends and family remembered” would be insufficient.⁵¹ This has been interpreted as implicitly establishing “the right to engage in advance planning for incapacity.”⁵² Also in 1990, the United States Congress passed the federal *Patient Self-Determination Act* which partially addresses the problem of educating both patients and doctors. It requires health-care institutions receiving federal funds to inform patients of their right to refuse life-sustaining treatments and to complete advance care directives.

(4) The failure of the living will?

2.25 Fagerlin and Schneider have asserted the failure of the living will in the United States.⁵³ They base their claim on a number of grounds, including the following. First, only 18% of Americans have living wills.⁵⁴ Moreover, while the chronically or terminally ill are more likely to draft living wills, a large percentage do not do so. In a study of dialysis patients, only 35% had a living will even though all of the participants thought that living wills were a “good idea.”⁵⁵ Such low figures can perhaps be attributed to a lack of education. Empirical studies have demonstrated that the *Patient Self Determination Act* has failed to generate a significant increase in advance directives, due to a

⁵¹ *Cruzan v Director, Missouri Department of Health* (1990) 497 US 261 at 266-268.

⁵² Gallagher “Advance Directives for Psychiatric Care: A Theoretical and Practical Overview for Legal Professionals” (1998) 4 Psychol Pub Pol’y & L 746 at 796.

⁵³ Fagerlin and Schneider “The Failure of the Living Will” (2004) *Hastings Centre Report* 30.

⁵⁴ Emanuel “Advance Directives for Medical Care; Reply” (1991) 321 NEJM 1256 cited *ibid*. In fact, the exact figure for Americans who have advance directives is uncertain. The Irish Council for Bioethics report that the US figures vary from approximately 20% to 25%, citing the following literature in support: Hecht and Shiel *Advance Medical Directives (Living Will, Power of Attorney and Health Care Proxy)*. Available at http://www.medicinenet.com/advance_medical_directives/article.htm; Crane Wittink and Doukas “Respecting End-of-Life Treatment Preferences 72(7) *American Family Physician* 1263; and The President’s Council on Bioethics *Taking Care – Ethical Caregiving in Our Aging Society* (Washington DC 2005) at 71.

⁵⁵ Holley et al “Factors Influencing Dialysis Patients’ Completion of Advance Directives” (1997) 30(3) *American Journal of Kidney Diseases* 356-360 cited in Fagerlin and Schneider “The Failure of the Living Will” (2004) *Hastings Centre Report* 30 fn 33 at 32.

passive implementation by medical staff and a lack of physician involvement.⁵⁶ Moreover, it has been estimated that the 1990 Act imposed a start-up cost of \$101,596,922 (omitting administration costs) on all hospitals. Fagerlin and Schneider argue that the 1990 Act should therefore be repealed as it was “passed with arrant and arrogant indifference to its effectiveness and its costs.”⁵⁷ Second, it has been submitted that people do not know what they actually want, analysing “their choices only superficially before placing them in a time capsule.”⁵⁸ A meta-analysis of eleven studies found that almost one-third of preferences for life-sustaining medical treatment changed over periods as short as two years.⁵⁹ Third, people cannot articulate their choices accurately. Most advance directive forms do not solve this problem as they have fail to ask all the right questions, and they ask those questions in a manner that fails to elicit a clear response.⁶⁰ Fourth, living wills had failed to stimulate conversation between doctor and patient about terminal treatment. In one study, doctors commonly “did not explore the reasons for patient’s preferences and merely determined whether they wanted specific interventions” with the average discussion lasting 5.6 minutes (physicians speaking for an average of 3.9 minutes and patients speaking for the remaining 1.7 minutes).⁶¹

⁵⁶ Yates and Glick “The Failed Patient Self-Determination Act and Policy Alternatives for the Right to Die” (1997) *Journal of Aging and Social Policy* 29 at 31 cited in Fagerlin and Schneider “The Failure of the Living Will” (2004) *Hastings Centre Report* 30 fn 33 at 32.

⁵⁷ Fagerlin and Schneider, “The Failure of the Living Will” (2004) *Hastings Centre Report* 30 fn 33 at 39.

⁵⁸ *Ibid* at 33.

⁵⁹ Coppola et al “Are Life-Sustaining Treatment Preferences Stable over Time? An Analysis of the Literature” unpublished manuscript cited in Fagerlin and Schneider *op cit* fn 33 at 34.

⁶⁰ Pope “The Maladaptation of Miranda to Advance Directives” (1999) 9(1) *Journal of Law-Medicine* 139 at 165-166 cited in Fagerlin and Schneider *op cit* fn 33 at 34.

⁶¹ Tulskey et al “Opening the Black Box: How Do Physicians Communicate about Advance Directives?” (1998) 129 *Annals of Internal Medicine* 441 at 444 cited in Fagerlin and Schneider “The Failure of the Living Will” (2004) *Hastings Centre Report* 30 fn 33 at 37.

D The English legal position

(1) The recognition of advance care directives at common law

2.26 The legal force of advance directives was first explicitly accepted in 1990 in *Re T*.⁶² Lord Donaldson MR delivered a significant judgment that highlighted the value of autonomy:

“An adult patient...who suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered...This right of choice is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent.”⁶³

2.27 Although the English Court of Appeal held that T’s refusal of treatment was vitiated by her mother’s undue influence, Lord Donaldson MR proceeded to consider the validity of a patient’s anticipatory refusal of treatment. He suggested that, in principle, advance decisions would be binding if three requirements were satisfied: first, the patient must be competent at the time the advance decision is made; second, the patient must have anticipated the circumstances when the advance decision would have effect and intend his decision to apply to those circumstances; finally, the patient must have reached his decision without undue influence.⁶⁴ However *Re T* has been described as something of a “false start” in terms of practical enforceability, in that Butler-Sloss and Staughton LJ held that a failure to act in accordance with an advance directive would give rise to only nominal damages.⁶⁵

2.28 Subsequently, in *Airedale NHS Trust v Bland*, the legal effect of anticipatory treatment decisions. Lord Keith stated:

“...a person 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...gives clear instructions....”⁶⁶

2.29 Lord Goff stated:

⁶² [1992] 4 All ER 649.

⁶³ [1992] All ER 649 at 652-653.

⁶⁴ *Ibid* at 664.

⁶⁵ Bartlett *Blackstone’s Guide to the Mental Capacity Act 2005* (Oxford University Press 2005) at paragraph 1.25 citing *Re T* [1992] 4 All ER 649 at 665, 669.

⁶⁶ [1993] 1 All ER 821 at 860 per Lord Keith.

“...a patient of sound mind may, if properly informed, require that life support should be discontinued...the same principle applies where the patient’s refusal to give his consent has been expressed at an earlier date.”⁶⁷

2.30 Of course, as Kennedy and Grubb state, in *Re T*, the Court of Appeal avoided giving effect to the patient’s wishes, and in *Bland*, the patient had not expressed any view about the treatment he should receive in the event of incompetence.⁶⁸ Therefore, to date, advance care directives have been held to be valid and effective in only two cases in England. In *Re C*,⁶⁹ 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. In *Re AK*,⁷⁰ 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 English High Court for 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.⁷¹

(2) Legislative history of the English Mental Capacity Act 2005

2.31 In 1992, Kings College London produced a study on *Advance Directives and AIDS* which surveyed the attitudes towards advance directives of a group of patients with HIV or AIDS and of the healthcare professionals caring for them. It identified the potential advantages and disadvantages associated with legislation.⁷² First, doctors might take an advance directive seriously if they were legally obliged to follow it due to a fear of the legal repercussions of non-

⁶⁷ [1993] 1 All ER 821 at 866b-e per Lord Goff.

⁶⁸ Kennedy and Grubb *Medical Law* (3rd ed Butterworths 2000) at 2036.

⁶⁹ [1994] 1 WLR 290.

⁷⁰ [2001] 1 FLR 129.

⁷¹ *Ibid* at 136.

⁷² Schlyter *Advance Directives and AIDS* (Centre of Medical Law and Ethics, Kings College London 1992) at 66-67.

compliance. Second, legislation could give doctors legal immunity for withdrawing or withholding treatment in accordance with an advance directive. Third, legislation could contain safeguards for the witnessing and storing of a directive in order to prevent undue influence. Potential disadvantages were also flagged, including potential rigidity in cases of life-sustaining treatment where decisions may have to be taken with a significant degree of flexibility to accommodate each individual case. However, doctors might feel obliged to comply with an advance directive for fear of legal consequences. A second disadvantage might be the creation of an air of mutual distrust between doctor and patient. Finally, it noted that an advance directive may in fact be illusory as it is the doctor who decides when the triggering event occurs, namely when a patient is in a terminal condition. Interestingly, it concluded that although a large majority of patients were in favour of advance directives having legal force, the doctors who participated in the study were largely opposed.

2.32 Subsequently, in its 1994 Report, the House of Lords Select Committee on Medical Ethics, whilst commending the development of advance directives, chose to reject calls for legislation:

“Adequate protection for doctors exists in terms of the current law and in trends in medical practice. We suggest that it could well be impossible to give advance directives in general greater legal force without depriving patients of the benefit of the doctor’s professional expertise and of new treatments and procedures which may have become available since the advance directive was signed.”⁷³

Instead it recommended that “the colleges and faculties of all the health-care professions should jointly develop a code of practice to guide its members.”⁷⁴ In 1995, the British Medical Association responded by producing a booklet entitled *Advance Statements About Medical Practice*.

In *Airedale NHS Trust v Bland*⁷⁵ Lord Browne-Wilkinson stated that he was in “no doubt that it is for Parliament, not the courts to decide the broader issues”.⁷⁶ The Law Commission also stated that

“The desirability of the piecemeal decision-making through case law is questionable. Decisions of the courts, particularly in sensitive areas, tend to be confined to the particular facts, and there is a

⁷³ House of Lords Select Committee on Medical Ethics (HL Paper 21-I 1994) at paragraph 264.

⁷⁴ *Ibid* at paragraph 265.

⁷⁵ [1993] 1 All ER 821

⁷⁶ *Ibid* at 878.

reluctance to give pronouncements on principles of general application. This can mean that there is no real consistency between different decisions, and can make it difficult to elicit guidelines with any real reliability.”⁷⁷

2.33 In 1995 *Report on Mental Incapacity*, the English Law Commission came down in favour of legislation on advance directives, noting that its consultation had “reflected an almost unanimous view that patients should be enabled and encouraged to exercise genuine choice about treatments and procedures.”⁷⁸ It acknowledged the reservations of the Select Committee and stated its intention to address them in its recommendations on legislative reform. Green and white papers followed in 1997 and 1999.⁷⁹ A draft Bill in 2003 received pre-legislative scrutiny, and a further draft Bill with explanatory notes was published in 2004. This latter Bill would eventually become law, seeking to “codify the current common law position on advance decisions to refuse treatment whilst at the same time increasing the safeguards attached to them.”⁸⁰

2.34 The English *Mental Capacity Act 2005* largely followed the Law Commission’s recommendations. Sections 24-26 of the 2005 Act codify the right of a competent individual to refuse medical treatment in advance. One of the five guiding principles of interpretation set out in section 1 of the 2005 Act is that any decisions must be made in the best interests of the person concerned. However, advance decisions differ from the other care provisions of the *Mental Capacity Act 2005*, in that once an advance decision to refuse treatment is valid and applicable, there is no place for a best interests assessment. Conversely, advance requests for treatment are not legally binding, and therefore will be taken into account when conducting a best interests determination. The 2005 Act is accompanied by a Code of Practice, which is in line with the

⁷⁷ The Law Commission for England and Wales *Mentally Incapacitated Adults and Decision-Making: An Overview Consultation Paper* (No 119 1991) at paragraph 3.37.

⁷⁸ The Law Commission for England and Wales *Report on Mental Incapacity* (No 231 1995) at paragraph 5.3.

⁷⁹ Lord Chancellor’s Department *Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults* Cm 3808 (1997); Lord Chancellor’s Department *Making Decisions: The Government’s Proposals for Making Decisions on Behalf of Mentally Incapacitated Adults* Cm 4465 (1999).

⁸⁰ *Overview of the Mental Incapacity Bill* (Department for Constitutional Affairs 2003). Available at <http://www.lcd.gov.uk/menincap/overview.htm> at 3-7.

recommendations of the Law Commission.⁸¹ It believed that a code of practice would be invaluable in addressing the many points of detail and practice that primary legislation could not hope to cover.⁸² Courts are to take departures from the Code of Practice into account, when relevant to a matter arising before them.⁸³

E Australia

2.35 In Australia, five of the eight Australian States and Territories have passed legislation recognising the right of a competent adult to make an advance care directive.⁸⁴ The common law continues to apply in the three jurisdictions that have not passed legislation.⁸⁵ For example, in Queensland, the *Powers of Attorney Act 1998* expressly states that the inherent jurisdiction of the Supreme Court of Queensland is not affected by its enactment.⁸⁶ Therefore, if guidance or a determination is needed regarding a decision to withhold or

⁸¹ *Mental Capacity Act 2005* – Code of Practice. Available at www.justice.gov.uk/guidance/mca-code-of-practice.htm. See chapter 9 in relation to advance decisions.

⁸² Law Commission of England and Wales *Report on Mental Incapacity* (No 231 1995) at paragraph 5.39. Section 42(1)(g) of the *Mental Capacity Act 2005* states that a code of practice must be prepared and issued with respect to advance decisions.

⁸³ Section 42(5) of the *Mental Capacity Act 2005*.

⁸⁴ *Medical Treatment Act 1988* (Vic); *Powers of Attorney Act 1988* (Qld); *Consent to Medical Treatment and Palliative Care Act 1995* (SA); *Medical Treatment Act 1994* (ACT); *Natural Death Act 1988* (NT).

⁸⁵ In New South Wales, legislation governing the completion of advance directives does not exist. However, the New South Wales Department of Health developed a document entitled 'Using Advance Care Directives' in 2004, which is designed to provide advice to health professionals. Available at <http://www.health.nsw.gov.au/pubs/2004/adcaredirectives.html>. In Tasmania, a private member's Bill, *Directions for Medical Treatment Bill*, was introduced into the Tasmanian Parliament in 2005. However, the Bill was not passed at the second reading speech stage on 21 June 2005 and therefore lapsed. In Western Australia, the *Acts Amendment (Advance Health Care Planning) Bill 2006* (WA) has been read for the second time in the Legislative Council on 6 December 2006. See Willmott "Advance Directives to Withhold Life-Sustaining Medical Treatment: Eroding Autonomy Through Statutory Reform" (2007) 10(2) *Flinders Journal of Law Reform* 287 at fn 8.

⁸⁶ Section 109 of the *Powers of Attorney Act 1998* (Qld).

withdraw life-sustaining measures, a person may pursue this either through the legislation or by relying on the inherent jurisdiction of the Supreme Court of Queensland. However, a number of issues have been left unresolved after the enactment of the *Powers of Attorney Act 1998*.⁸⁷ For example, the common law that existed before the Act came into force was simply 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.”⁸⁸ This right to refuse could operate even if the refusal was given in advance of the relevant medical situation.⁸⁹

2.36 The *Powers of Attorney Act 1998* provides that certain formalities must be met in order for an advance health directive to be valid. The Queensland Law Reform Commission recommended preserving the common law on the basis that it would “maximise the opportunity for people to exercise control over their future medical treatment.”⁹⁰ It has also been argued that as common law is less formal, it would promote advance care planning to a larger extent.⁹¹ However, in recognising common law directives, a two-tier system would be created under which both statutory health directives and common law directives would operate. “This might lead to unnecessary uncertainty and could undermine any restrictions which the legislation attempted to impose.”⁹²

⁸⁷ White and Willmott “Rethinking Life-Sustaining Measures: Questions for Queensland” (February 2005). Available at www.eprints.qut.edu.au/archive/00007093/

⁸⁸ *Re MB (medical treatment)* [1997] 2 FLR 426 at 432 per Butler-Sloss LJ.

⁸⁹ *Re C (adult: refusal of medical treatment)* [1994] 1 All ER 819.

⁹⁰ Queensland Law Reform Commission *Assisted and Substituted Decisions: Decision-Making By and For People with a Decision-Making Disability* (Report No 49 1996 Vol 1). The *Powers of Attorney Act 1998* is largely based on recommendations made by the Queensland Law Reform Commission.

⁹¹ White and Willmott “Rethinking Life-Sustaining Measures: Questions for Queensland” (February 2005) at 26. Available at www.eprints.qut.edu.au/archive/00007093/

⁹² Queensland Law Reform Commission *Assisted and Substituted Decisions: Decision-Making By and For People with a Decision-Making Disability* (Report No 49 1996 Vol 1).

F Hong Kong

2.37 The Law Reform Commission of Hong Kong recommended in its 2006 Report on this issue that advance directives should be promoted by non-legislative means, including the wide dissemination of a model form of advance directive based on three considerations.⁹³ First, it argued that the publication and dissemination of a model form could be achieved quickly and cost-effectively, offering “immediate assistance to patients, their families and medical practitioners, without the delays inherent in the legislative process.”⁹⁴ Second, it acknowledged that although Hong Kong law recognises the validity of advance directives, it was still unclear as to what form such a directive should take. Finally, it noted that the community was not generally familiar with the concept of advance directives. Therefore, it would be “premature to attempt to formulate a statutory framework and to embark on the legislative process, without greater public awareness of the issues involved.”⁹⁵

2.38 In order to generate such awareness of the concept of advance directives, the Commission recommended that the Government should launch publicity programmes enlisting the support of organisations such as the Medical Council, the Bar Association, the Law Society, the Hospital Authority, all hospitals and medical clinics, non-governmental organisations involved in care for the elderly, and religious and community groups.

2.39 Once the community has become familiar with the concept of advance directives, the Commission recommended that the Government should then review the position of advance directives and consider the appropriateness of legislation, taking three factors into consideration, namely: “how widely the use of advance directives had been taken up; how many disputes had arisen; and the extent to which people had accepted the model form of advance directive.”⁹⁶

⁹³ The Law Reform Commission of Hong Kong *Report on Substitute Decision-Making and Advance Directives in Relation to Medical Treatment* August 2006 at <http://www.hkreform.gov.hk>

⁹⁴ *Ibid* at paragraph 8.36.

⁹⁵ The Law Reform Commission of Hong Kong *Report on Substitute Decision-Making and Advance Directives in Relation to Medical Treatment* August 2006 at <http://www.hkreform.gov.hk>.

⁹⁶ *Ibid*, recommendation 1 at paragraph 8.40

G Europe

(1) The European Convention on Human Rights

2.40 The *European Convention on Human Rights* does not contain any direct reference to an advance refusal of medical treatment. It has been argued that the key articles are Articles 3 and 8.⁹⁷

2.41 Article 3 prohibits torture and inhuman or degrading treatment or punishment. ‘Degrading treatment’ has been defined in the following terms:

“Treatment or punishment of an individual may be said to be degrading if it grossly humiliates him before others or drives him to act against his will or conscience.”⁹⁸

Two points should be noted in this respect. First, in the *Herczegfalvy* case, the European Court of Human Rights held that “a measure which is a therapeutic necessity cannot be regarded as inhuman or degrading. The Court must nevertheless satisfy itself that the medical necessity has been convincingly shown to exist.”⁹⁹ Therefore, if medical treatment is therapeutically necessary, it will not violate Article 3 even if it is imposed without consent. Second, in *NHS Trust A v M; NHS Trust B v H*, the English High Court noted that Article 3 requires the patient to be aware of the inhuman and degrading treatment which he or she is experiencing. Therefore, as a patient who is in a permanent vegetative state has “no feelings and no comprehension of the treatment accorded to him or her”, he or she cannot obtain the protection of Article 3.¹⁰⁰ There was a brief diversion from this point of view, in the judgment of Munby J in the English case of *R (Burke) v GMC*.¹⁰¹ He held that that Article 3 could be violated even if the individual concerned was unaware of the humiliating or degrading treatment which he is experiencing. He felt that the definition of torture and degrading treatment should not be viewed from the point of view of the individual concerned, but rather should be viewed objectively, from the point of view of the reasonable bystander.¹⁰² The English Court of Appeal curtly dismissed this part of his judgment on the basis that in Mr Burke’s case, artificial

⁹⁷ Wicks “Refusal of Medical Treatment and ECHR” (2001) 9 *Medical Law Review* 17.

⁹⁸ *Denmark, Norway, Sweden and the Netherlands v Greece* (1969) 12 YB 1 at 186.

⁹⁹ *Herczegfalvy v Austria* (1992) Series A No 244 at paragraph 82.

¹⁰⁰ *NHS Trust A v M; NHS Trust B v H* [2001] 1 All ER 801 at 814 per Butler-Sloss P.

¹⁰¹ *R (on the application of Burke) v General Medical Council* [2004] EWHC 1879 (Admin).

¹⁰² *Ibid* at paragraph 149-150.

nutrition and hydration would only be necessary while he was still competent, and therefore, it:

“[did] not consider that there was any justification for embarking on speculation as to what the position might be when Mr Burke reaches the final stages of his life.”¹⁰³

2.42 More specifically, a patient’s right to refuse life-sustaining medical treatment can be founded on his or her right to private life in Article 8(1) of the Convention. In *Pretty v United Kingdom*, the European Court of Human Rights stated that:

“In the sphere of medical treatment, the refusal to accept a particular treatment might, inevitably, lead to a fatal outcome, yet the imposition of medical treatment, without the consent of a mentally competent adult patient, would interfere with a person’s physical integrity in a manner capable of engaging the rights protected under Article 8(1) of the Convention.”¹⁰⁴

However, Article 8(1) may be subject to interference if “necessary in a democratic society” by virtue of Article 8(2). Thus, a balancing exercise between the right of the individual in Article 8(1) and the legitimate aims specified in Article 8(2) might require a balance to be struck on an individual case by case basis. Conversely, under common law, that balance is always struck in favour of the individual’s right to refuse treatment which is “paramount”.¹⁰⁵ Therefore, it has been argued that English common law is probably “more robust in its recognition of a competent patient’s right to refuse life-sustaining medical treatment than is the ECHR.”¹⁰⁶

(2) *The European Convention on Human Rights and Biomedicine 1997*

2.43 In contrast to the *European Convention on Human Rights*, the 1997 *European Convention on Human Rights and Biomedicine* contains an article on “previously expressed issues”. The Convention has at its core the protection of the dignity and integrity of human beings in the area of biological and medical

¹⁰³ *R (Burke) v GMC* [2005] EWCA Civ 1003; [2005] 2 FLR 1223 at paragraph 37.

¹⁰⁴ *Pretty v United Kingdom* (2002) 35 EHRR 1 at paragraph 63.

¹⁰⁵ *Re T (adult: refusal of medical treatment)* [1992] 4 All ER 649 at 661 per Lord Donaldson MR.

¹⁰⁶ Grubb “Competent Adult Patient: Right to Refuse Life-Sustaining Treatment” (2002) 10 *Medical Law Review* 201 at 203.

advances.¹⁰⁷ While the majority of the Council of Europe members have signed and ratified this Convention, Ireland has not done so to date. According to Article 9:

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

2.44 Paragraph 62 of the explanatory report to the 1997 Convention states that:

“...taking previously expressed wishes into account does not mean that they should necessarily be followed. For example, when the wishes were expressed a long time before the intervention and science has since progressed, there may be grounds for not heeding the patient’s opinion. The practitioner should thus, as far as possible, be satisfied that the wishes of the patient apply to the particular situation and are still valid, taking into account in particular of technical progress in medicine.”

Article 9 is not limited to advance refusals, but also encompasses advance consent to treatments. However, the right to refuse treatment in advance is only “weakly recognised” as Article 9 merely requires the previously expressed wishes of a patient to be taken into account. Nys has argued that the Convention adopted this cautious approach in order to reflect the lack of consensus in many European countries as to the validity of an advance refusal of treatment.¹⁰⁸

H Manitoba

(1) Principles and procedures

2.45 In December 2003, the Manitoba Law Reform Commission issued a report on *Withholding or Withdrawing Life-Sustaining Medical Treatment*.¹⁰⁹ The Commission considered that certain fundamental principles and policies should

¹⁰⁷ The Council of Europe agreed the *Convention on Human Rights and Biomedicine*, also known as the Oviedo Convention, on April 4 1997, and it entered into force on December 1, 1999. See Nys et al “Patient Rights in EU Member States After the Ratification of the Convention on Human Rights and Biomedicine” (2007) 83 *Health Policy* 223.

¹⁰⁸ Nys “Physician Involvement in a Patient’s Death: A Continental European Perspective” (1999) 7(2) *Medical Law Review* 208.

¹⁰⁹ Manitoba Law Reform Commission *Report on Withholding or Withdrawing Life-Sustaining Medical Treatment* (No 109 2003).

be reflected in the rules or framework controlling the withholding or withdrawal of life-sustaining medical treatment. Some of the principles and procedures are:

- There must be a uniform approach and process to withholding or withdrawing life sustaining medical treatment in all health care institutions.
- The decision-making process must be clear and transparent and must be communicated clearly not only to the patient and his or her family but also to the public in order to facilitate a broad understanding of how these decisions are made.
- Emphasis must be placed on the process for decision-making rather than the formulation of specific rules which would purport to dictate the decision. The process must be designed to facilitate an agreement between the physician and the patient or his or her substitute decision-maker.
- Where there is disagreement between the physician and the patient or substitute decision-maker on the appropriate course of action, the patient must be given an opportunity to secure an independent second opinion from a physician who is not a member of the patient's health care team and/or request that his or her care be transferred to another willing physician.
- The Commission did not favour a right to indefinite life-sustaining medical treatment. The appeal of autonomous decision-making and personal control of all end-of-life medical decision making is initially attractive, but an unfettered right to life-sustaining treatment may result in unreasonable demands being made for indefinite inappropriate medical treatment.
- Final resort to the courts will remain available where the procedures designed to achieve consensus have irretrievably broken down.¹¹⁰

(2) Final recommendations

2.46 The Manitoba Law Reform Commission did not favour a legislative implementation of these principles. Rather:

“[i]ts preference is to see them embodied in a statement or by-law of the College of Physicians and Surgeons of Manitoba...We also recommend that other health care institutions, agencies, associations and bodies involved in delivering health care in Manitoba should adopt the policy of the College once amended to reflect our advice.

¹¹⁰ Manitoba Law Reform Commission *Report on Withholding or Withdrawing Life-Sustaining Medical Treatment* (No 109 2003) at 108.

We urge them to use the Policy as a template for their own protocols and procedures...We envisage a cohesive and integrated approach to maximise consensus decision-making without imposing an obligation on physicians to provide inappropriate medical care. Such an approach, coupled with an extensive program of public education and awareness of the end-of-life decision-making process, will serve the citizens of Manitoba well.”¹¹¹

I Conclusion

2.47 Irish Common Law may recognise an advance care directive on the basis of the views expressed by the Supreme Court in *Re a Ward of Court (No 2)*,¹¹² but in the Commission’s view, the lack of clear guidance to date illustrates the need for legislation. Clarity is required on who can make healthcare decisions for an incompetent patient, what form an advance care directive may take and also whether a person’s family can make a decision on his or her behalf. In this respect, the Commission provisionally recommends that advance care directives be placed on a statutory footing. The Commission also provisionally recommends that, in view of the complexity associated with the many issues that arise in this context, a set of guidelines be drawn up to complement the legislative framework.

2.48 *The Commission provisionally recommends that advance care directives be placed on a statutory footing. The Commission provisionally recommends that a set of guidelines be drawn up to complement the legislative framework.*

J Advance care directives refusing treatment on religious grounds

(1) Ireland

2.49 Denham J expressly enshrined the right of a competent adult to refuse any medical treatment in *Re a Ward of Court (No 2)*:

“The right to life is the pre-eminent personal right. The State has guaranteed in its laws to respect this right. The respect is absolute. This right refers to all lives – all lives are respected for the benefit of the individual and for the common good. The State’s respect for the life of the individual encompasses the right of the individual to, for

¹¹¹ Manitoba Law Reform Commission *Report on Withholding or Withdrawing Life-Sustaining Medical Treatment* (No 109 2003) at 108.

¹¹² [1996] IR 79

example, refuse a blood transfusion for religious reasons. In the recognition of the individual's autonomy, life is respected."¹¹³

2.50 In *Fitzpatrick v FK*,¹¹⁴ the High Court ordered 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. Ms K had suffered a massive post partum haemorrhage following the birth of her son at the Coombe Hospital. However, she refused an urgent blood transfusion on the basis that she was a Jehovah's Witness. Abbott J stated that Ms K was competent to make healthcare decisions. However, he found that the welfare of her newly-born child, with no other apparent parent, was paramount and should override the wishes of his mother. In erring on the side of preserving life, he made an *ex parte* order, directing the hospital to do everything in its power to save the life of the woman including, if necessary, restraining her if she physically attempted to stop doctors administering to her the transfusion.

2.51 The order sparked a heated debate, and was considered to be "something of a new departure in the area of non-consensual medical treatment."¹¹⁵ The High Court had previously ordered transfusions to be administered in cases where there was either a 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 a minor nor incapacitated. The court had effectively balanced personal autonomy against the interests of the newborn child to the extent that it could override the refusal of treatment of a *compos mentis* adult.¹¹⁶ Powers has questioned whether the Court had considered section 4(2) of the *Health Act 1953* which states that:

"Any person who avails himself of any service provided under this Act shall not be under any obligation to submit himself...to a health

¹¹³ [1996] 2 IR 79 at 160.

¹¹⁴ [2006] I.E.H.C. 392; [2008] ILRM 68.

¹¹⁵ Power "Bioethics and the Middle of Life" (2007) 12(6) *Bar Review* 212 at 214.

¹¹⁶ Sheikh "Medico-Legal Issues and Patient Autonomy – Here Yesterday Gone Tomorrow?" (2006) 12(2) *Medico-Legal Journal of Ireland* 54. See also Hayes "Religious Objections to Blood Transfusions" (2008) Jan/Feb *Law Society of Ireland Gazette* 20. For an interesting perspective on the compatibility of advance care directives with Islamic teachings see Khan "Religious Teachings and Reflections on Advance Directives – Religious Values and Legal Dilemmas in Bioethics: An Islamic Perspective" (2002) 30 *Fordham Urban Law Journal* 267.

examination or treatment which is contrary to the teaching of his religion.”¹¹⁷

2.52 It was unsurprising therefore, that when the issue was argued by both parties in *Fitzpatrick v FK (No 2)*¹¹⁸ in 2008, the judgment of Laffoy J commenced by addressing the “novelty of the core issue”, namely, whether a court may intervene in the case of a patient, who is an adult and is not incompetent mentally “who has refused medical treatment, and by order authorise the hospital...to administer such treatment to the patient.”¹¹⁹ She held that Ms K’s capacity was impaired to the extent that she did not have the ability to make a valid refusal to accept the blood transfusion based on the objective evidence before her.¹²⁰ As it was not a valid refusal, the question of balancing rights of her new-born baby under the Constitution against her constitutional rights of self-determination and free practice of her religion did not fall to be considered.

(a) Refusing life-sustaining treatment on religious grounds on behalf of minor children

2.53 Although the State’s respect for the life of the individual encompasses the right of the individual to refuse a blood transfusion for religious reasons, it would appear that parents do not have the right to refuse life-sustaining treatment on behalf of minor children. Article 41.1.1° of the Constitution states:

“The State recognises the Family as the natural primary and fundamental unit group of Society, and as a moral institution possessing inalienable and imprescriptible rights, antecedent and superior to all positive law.”

However, Article 42.5 provides that:

“In exceptional cases, where the parents for physical or moral reasons fail in their duty towards their children, the State as guardian of the common good, by appropriate means shall endeavour to supply the place of the parents, but always with due regard for the natural and imprescriptible rights of the child.”

¹¹⁷ Power “Bioethics and the Middle of Life” (2007) *Bar Review* 212 at 214.

¹¹⁸ [2008] I.E.H.C. 104.

¹¹⁹ *Fitzpatrick v FK* [2008] IEHC 104 High Court (Laffoy J) 25 April 2008.

¹²⁰ See paragraphs 3.25-3.29 below.

2.54 In *North Western Health Board v HW*,¹²¹ the plaintiff board sought an order permitting it to carry out a PKU test on an infant against the wishes of the child's parents. The parents' objection was originally based on their religious belief that nobody should be allowed to injure anyone else,¹²² but ultimately rested on their view that their child should not be subjected to the invasive process of puncturing a blood vessel, preferring that his hair or urine be tested instead. The Supreme Court, by a four to one majority, upheld the High Court decision not to grant such an order. The court held that the infant did not have a real or significant chance of having any of the diseases being screened in the test, therefore suggesting that State intervention was permissible when a child faced an imminent threat to life or serious injury. Denham J observed that any intervention by the courts in the "delicate filigree of relationships within the family has profound effects".¹²³ She held that:

"The State...may intervene in the family, may interfere with the rights of family as a unit, and the rights of the child and parents pursuant to Article 41 of the Constitution, if it is justified pursuant to Article 42.5 when parents have failed for physical or moral reasons in their duty to their children or when other constitutional rights of the child are breached or in danger of being breached."¹²⁴

An illustration of an "exceptional case" would be a surgical or medical procedure in relation to an imminent threat to life or serious injury."¹²⁵ In the present case, the court was not satisfied that it was an "exceptional case". It had not been established that the parents had failed in their duty to the child so that the child's constitutional rights would be infringed.

¹²¹ [2001] 3 IR 622. See Arthur "North Western Health Board v HW and CW – Reformulating Irish Family Law" (2002) 3 ILT 39 who recommends that parents should not enjoy absolute power over children, but rather have a 'parental responsibility' of raising the child to moral, physical and emotional health; Martin "Parental Rights to Withhold Consent to Medical Treatment for Their Child: A Conflict of Rights?" (2001) 7 ILT 114 who discusses the High Court judgment of McCracken J; and Mills "Constitutional Law – PKU: Please Keep Unclear" (2001) 8(1) DULJ 180 who notes that the position of the mature minor still needs to be addressed.

¹²² A view with which Murphy J declared himself "impatient": [2001] 3 IR 622 at 731.

¹²³ [2001] 3 IR 622 at 724.

¹²⁴ *Ibid* at 727.

¹²⁵ *Ibid*.

2.55 In 2008 in *Health Service Executive v C and D*,¹²⁶ Laffoy J granted the HSE an order allowing doctors to administer blood transfusions or other treatments considered “medically necessary” to twin babies after their birth in order to avoid death or serious injury.¹²⁷ The twins, who were unborn at the time of the order, were severely anaemic and would require transfusions within minutes of being prematurely induced, in order to avoid risk of death or serious injury. Their parents, as Jehovah’s Witnesses, had objected to blood products on religious grounds but agreed to abide by the court order.

2.56 The order made by Laffoy J would appear to be in line with the approach taken in other jurisdictions towards parents who refuse medical treatment on religious grounds on behalf of their children. In *Prince v Massachusetts*,¹²⁸ the Supreme Court of the United States held that:

“The right to practice religion freely does not include liberty to expose the community or the child to communicable diseases or the latter to ill health or death....Parents may be free to become martyrs themselves. But it does not follow they are free in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.”¹²⁹

Similarly, in *Re R (a minor) (blood transfusion)*,¹³⁰ the English High Court made an order under section 8 of the *Children Act 1989* overriding the “scriptural conscience” of Jehovah’s Witness parents that had led them to reject life-saving blood products for their 10-month old infant who was suffering from leukaemia. Booth J directed that blood products should only be administered in an “imminently life-threatening” situation where there is no reasonable alternative. In any “less than imminently life-threatening” situation doctors should consult with the parents considering “at every opportunity all available forms of management suggested by the parents.”¹³¹ However, Bridge is highly critical of an approach that “compromises the child in all but the last resort in order to keep faith with the parental convictions and their perception of how welfare may best be enhanced.” She argues that by adopting such a sympathetic approach

¹²⁶ The Irish Times 25 April 2008.

¹²⁷ *Ibid*

¹²⁸ (1944) 321 US 158.

¹²⁹ *Ibid* at 170. See Diaz “Refusal of Medical Treatment Based on Religious Beliefs: Jehovah’s Witness Parents” (2007) 16 *Journal of Contemporary Legal Issues* 85.

¹³⁰ [1993] 2 FLR 757.

¹³¹ *Ibid* at 761.

to the religious convictions of parents, further harm will result to the child while “clinicians dither about whether or when to seek legal intervention.”¹³²

2.57 While such criticisms may be valid, the courts must adhere to the constitution. The courts have recognised that the child has rights:

“Having been born, the child has the right to be fed and to live, to be reared and educated, to have the opportunity of working and of realising his or her full personality and dignity as a human being. These rights of the child (and others which I have not enumerated) must equally be protected and vindicated by the State.”¹³³

Article 42.5 of the Constitution does however state that

“In exceptional cases, where the parents for physical or moral reasons fail in their duty towards their children, the State as guardian of the common good, by appropriate means shall endeavour to supply the place of the parents but always have due regard for the natural and imprescriptible rights of the child.”

Hardiman J in *N v Health Service Executive*¹³⁴ (the Baby Ann case) stated that the threshold before the state may interfere was a high one. He felt that

“The effect of our constitutional dispensation is that, presumptively, the right to form a view of the child’s welfare and to act on it belongs to the parents.”¹³⁵

Thus as the Constitution stands, unless there are exceptional circumstances the court may not intervene. McGuinness J reached the same outcome as she felt that the evidence before the High Court did not establish that “there were compelling reasons that her welfare could not be achieved in the custody and care of her natural parents”.¹³⁶ This, coupled with the fact that the adoption could not go ahead due to the marriage of baby Ann’s parents, led her to reach this conclusion.

(2) England and Wales

2.58 The Code of Practice for the English *Mental Capacity Act 2005* makes explicit reference to advance decisions refusing all treatment in any

¹³² Bridge “Religion Culture and Conviction – The Medical Treatment of Young Children” (1999) *Child and Family Law Quarterly* 1.

¹³³ *Per* O’Higgins CJ in *G v An Bord Uchtála* [1980] 1 IR 32 at 55-56

¹³⁴ [2006] 4 IR 374

¹³⁵ *Ibid* at 504

¹³⁶ *Ibid* at 498.

situation based on religious beliefs in that they may be valid and applicable.¹³⁷ This would seem to be in accordance with English case law.

2.59 One of the leading cases involving an adult Jehovah's Witness was *Re T*.¹³⁸ T was injured in a car accident when she was 34 weeks pregnant. T had been brought up by her mother, a devout Jehovah's Witness, although T was not herself a member of that religious sect. After a private conversation with her mother in hospital, T informed hospital staff that she did not want a blood transfusion. Shortly afterwards she went into labour, and due to her distressed condition, she was advised that a Caesarian section was necessary. After another private conversation with her mother, T repeated that she did not want a blood transfusion and inquired as to alternative treatment. She then signed a form of refusal of consent to blood transfusions, but it was not explained to her that a transfusion might be necessary to save her life. Following the operation, her condition deteriorated and a transfusion was essential to save her life. In an emergency hearing, the judge authorised the administration of a transfusion on the basis her medical condition had made T unfit to make a genuine decision. Moreover, her decision had been reached under the influence of her mother to the extent that it was not voluntary. The Court of Appeal held that on the facts, T's refusal of treatment was vitiated by her mother's undue influence.

2.60 In *McGovern v Royal Devon and Exeter Healthcare NHS Trust*,¹³⁹ an unreported out of court settlement in September 2004, a 56-year old renal patient received £8,500 for a blood transfusion that was carried out without his consent three years previously. The patient, a Jehovah's Witness, had been attending the hospital for 20 years, had previously refused a blood transfusion in life-threatening situations, and this was clearly marked on his medical records. As a result of the transfusion, the patient had suffered psychological injury as a result of knowing that the transfusion was contrary to his religion.

(3) Canada

2.61 In *Malette v Shulman*¹⁴⁰ an emergency-room doctor gave a blood transfusion to a severely injured and unconscious patient despite the fact that she carried a card stating:

"NO BLOOD TRANSFUSION!"

¹³⁷ *Mental Capacity Act 2005 – Code of Practice* at paragraph 9.13.

¹³⁸ [1992] 4 All ER 649.

¹³⁹ (2004) unreported. See Burns "Bad Blood" (2007) *New Law Journal* 1722 at 1723.

¹⁴⁰ (1990) 67 DLR (4th) 321.

As one of Jehovah's Witnesses with firm religious convictions, I request that no blood or blood products be administered to me under any circumstances. I fully realise the implications of this position, but I have resolutely decided to obey the Bible command: 'Keep abstaining...from blood' (Acts 15:28, 29). However, I have no religious objection to use the nonblood alternatives such as Dextran, Haemaccel, PVP, Ringer's Lactate or saline solution."

Donnelly J held that the instructions on the card should have been followed even though the card was neither witnessed nor dated. He awarded substantial damages for mental distress which was upheld on appeal:

"However sacred life may be, fair social comment admits that certain aspects of life are properly held to be more important than life itself. Such proud and honourable motivations are long entrenched in society, whether it be patriotism in war, duty by law enforcement officers, protection of the life of a spouse, son or daughter, death before dishonour, death before loss of liberty, or religious martyrdom. Refusal of medical treatment on religious grounds is such a value."¹⁴¹

(4) The European Convention on Human Rights

2.62 Article 9 of the ECHR states that everyone has the right to freedom of thought, conscience and religion, including a right to manifest one's "religion or belief, in worship, teaching, practice and observance." Wicks cites the case of *Hoffmann v Austria*¹⁴² in support of her argument that refusing consent to medical treatment may be a manifestation of religion.¹⁴³ There, the applicant argued that she had been denied custody of her children because she was a Jehovah's Witness and would have refused blood transfusions for her children. The European Court of Human Rights accepted that the applicant's refusal of blood transfusions was a direct consequence of her religious beliefs, thereby apparently accepting that "Article 9(1) may *prima facie* protect a refusal by Jehovah's Witnesses to consent to blood transfusions."¹⁴⁴

(5) Conclusion

2.63 In light of this discussion, the Commission provisionally recommends that a refusal to consent to treatment on religious grounds will in general

¹⁴¹ (1990) 67 DLR (4th) 321 at 47.

¹⁴² (1993) Series A, No 106, paragraph 50.

¹⁴³ Wicks "The right to refuse medical treatment under the European Convention on Human Rights" (2001) 9 *Medical Law Review* 17 at 30.

¹⁴⁴ *Ibid* at 31.

(subject to constitutional considerations) constitute a valid advance care directive.

2.64 The Commission provisionally recommends that a refusal to consent to treatment on religious grounds will in general (subject to constitutional considerations) constitute a valid advance care directive.

CHAPTER 3 INFORMED DECISION MAKING AND CAPACITY TO MAKE ADVANCE CARE DIRECTIVES

A Introduction

3.01 In this Chapter, the Commission discusses informed decision-making and the capacity to make advance care directives. Part B discusses the importance of ensuring that any medical treatment decision, whether contemporaneous or anticipatory, is sufficiently informed and whether it should be a mandatory requirement to receive advice while drafting an advance care directive. Part C discusses the capacity to make a healthcare decision, and the importance of Laffoy J's recent judgment in the *K* case. Part D considers the age at which a person should be considered competent to refuse treatment in an advance care directive setting.

B Informed decision making and the provision of information

(1) Ireland

3.02 Any medical treatment decision, whether contemporaneous or anticipatory, must be sufficiently informed. Kirby J, in 1983, defined informed consent as:

“That consent which is obtained after the patient has been adequately instructed about the ratio of risk and benefit involved in the procedure as compared to alternative procedures or no treatment at all.”¹

As the Commission noted in its *Consultation Paper on Vulnerable Adults and the Law: Capacity*, if medical treatment is carried out without informed consent, this has implications for the Constitution, human rights law, the law of torts and criminal law.² Therefore, given the importance accorded to the concept of informed consent in Irish law, should it be a statutory requirement that

¹ Kirby “Informed Consent: what does it mean?” (1983) 9(2) *Journal of Medical Ethics* 69.

² Law Reform Commission *Consultation Paper on Vulnerable Adults and the Law: Capacity* (LRC CP 37-2005) at paragraph 7.08.

individuals avail of advice and counselling before drafting an advance care directive?

3.03 In its ethical guidelines, the Medical Council advises 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 this consent the doctor must satisfy himself/herself that the patient understands what is involved by explaining in appropriate terminology. A record of this discussion should be made in the patient’s notes.”³

3.04 There is no general statutory embodiment of the common law requirement of informed consent to medical treatment. However, section 56 of the *Mental Health Act 2001* sets out a useful statutory definition of what constitutes consent in the specific context of treatment for a ‘mental disorder’ of a patient covered by the legislation:

“...‘consent’, in relation to a patient, means .consent obtained freely without threats or inducement, where –

- (a) The consultant psychiatrist responsible for the care and treatment of the patient is satisfied that the patient is capable of understanding the nature, purpose and likely effects of the proposed treatment; and
- (b) The consultant psychiatrist has given the patient adequate information, in a form and language that the patient can understand, on the nature, purpose and likely effects of the proposed treatment.”

3.05 The Commission has previously concluded that informed consent essentially requires that the following elements be satisfied:⁴

- prior disclosure of sufficient relevant information by the medical practitioner to the patient to enable an informed decision to be made about the treatment proposed;
- the patient has the necessary capacity at the time to decide whether or not to consent to the proposed treatment;

³ Irish Medical Council *A Guide to Ethical Conduct and Behaviour* (6th ed 2004) at paragraph 17.1.

⁴ Law Reform Commission *Consultation Paper on Vulnerable Adults and the Law: Capacity* (LRC CP 37-2005) at paragraph 7.05.

- the context allows the patient to voluntarily make a decision as to whether to consent to or to decline the proposed treatment.

(2) England and Wales

(a) Common law

3.06 In the English case *Re T*,⁵ Lord Donaldson specifically observed in relation to advance directives that:

“What is required is that the patient knew in broad terms the nature and effect of the procedure to which consent (or refusal) was given. There is indeed a duty on the part of doctors to give the patient appropriately full information as to the nature of the information proposed, the likely risks, including any special risks attaching to the treatment being administered by particular persons), but a failure to perform this duty sounds in negligence and does not, as such, vitiate a consent or refusal.”⁶

3.07 This statement has been the source of debate. Whilst some commentators have accepted that it invokes a common law requirement that an adult must be sufficiently informed before an advance refusal of treatment will operate, others have argued that such a requirement simply does not exist.⁷ They would argue that it conflicts with the fundamental proposition set out by Butler-Sloss LJ in *Re MB*⁸ 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.”⁹

(b) Mental Capacity Act 2005

3.08 During the passage of what became the *Mental Capacity Act 2005*, it was proposed that “an advance statement must be formulated with adequate information from a doctor familiar with the patient’s clinical situation.”¹⁰ However,

⁵ [1992] 4 All ER 649.

⁶ *Ibid* at 663.

⁷ Willmott, White and Howard “Refusing Advance Refusals: Advance Directives and Life-Sustaining Treatment” (2006) 30 *Melbourne University Law Review* 211, at 221.

⁸ [1997] 2 Fam Law R 426.

⁹ *Ibid* at 432.

¹⁰ Standing Committee A ‘*Mental Capacity Bill: Advance Decisions to Refuse Treatment: General*’ Hansard 28 October 2004 Column No 199 at column 202.

the British government chose not to include this procedural requirement in the English *Mental Capacity Act 2005*. The Code of Practice made under the 2005 Act merely recommends that advance decisions are made with advice from healthcare professionals or organisations that can provide advice on specific conditions or situations.¹¹ With regard to advance decisions refusing life-sustaining treatment, the Code of Practice recommends that it is particularly important for the maker to discuss it fully with a healthcare professional. This is to clarify not only what treatment is considered to be life-sustaining, but also to be fully informed of the implications of refusing such treatment and what may happen as a result.¹² It was felt that to impose a mandatory requirement upon patients to be sufficiently well informed to make an advance decision would be “inappropriate and unduly intrusive.”¹³ However, commentators felt that “the enhanced security of the advance directive regarding what is a fundamental life choice” would justify “the relatively minor infringement of autonomy in requiring medical advice.”¹⁴

(3) Mandatory requirement to receive advice

3.09 In the Australian Capital Territory, section 11(1) of the *Medical Treatment Act 1994* (ACT) imposes an obligation on the health care professional to advise the adult about his or her illness, alternative forms of treatment, the consequences of the treatment and the consequences of remaining untreated. There are a number of advantages associated with obtaining professional advice and counselling whilst drafting an advance directive.

3.10 First, advance directives that are arrived at after consultation with a doctor, and drawn up at a time when the patient and his doctor have the patient’s prognosis and treatment options in mind will be more likely to be found valid and applicable.¹⁵ For example, in *W Healthcare NHS Trust v H*,¹⁶ the English Court of Appeal held that an alleged advance decision to withdraw

¹¹ *Mental Capacity Act 2005 - Code of Practice*, at paragraph 9.14. Available at <http://www.justice.gov.uk/guidance/mca-code-of-practice.htm>.

¹² *Mental Capacity Act 2005 – Code of Practice* at paragraph 9.27.

¹³ Included as an appendix to The Joint Committee on Human Rights *15th Report of Session 2004-05* (2005). Available at <http://www.publications.parliament.uk/pa/jt200405/jtselect/jtrights/97/9702.htm>.

¹⁴ Maclean “Advance Directives and the Rocky Waters of Anticipatory Decision-Making” (2008) 16(1) *Medical Law Review* 1 at 15.

¹⁵ Grubb “United Kingdom” [1993] 1(1) *Medical Law Review* 84 at 87.

¹⁶ [2005] 1 WLR 834.

treatment was not legally binding on the grounds that the patient had not discussed the ramifications of slowly starving to death over a two-to three-week period with doctors.¹⁷ Where a patient refuses life-sustaining treatment in an advance directive, the need to be fully informed of the full implications of such a decision takes on an added importance when considering the words of Munby J in *HE v A Hospital NHS Trust*¹⁸:

“Where, as here, life is at stake, the evidence must be scrutinised with especial care. The continuing validity and applicability of the advance directive must be clearly established by convincing and inherently reliable evidence.”¹⁹

3.11 Second, the British Medical Association has also noted that individuals may have unrealistic expectations with regard to what certain treatments can or cannot do for them, which could influence the wording of their advance care directives.²⁰

3.12 Third, the Irish Council for Bioethics has noted that it is important to be specific in outlining preferences for particular treatment scenarios, and that this level of expected specificity could be difficult to achieve without adequate counselling.²¹ Moreover, evidence from the U.S. demonstrates that advance directives are not always informed decisions.²² For example, 10 out of 28 participants in an advance planning workshop agreed with both of the following inconsistent statements: “I would never want to be on a respirator” and “If a short period of extremely intensive medical care could return me to a near-normal condition, I would want it.”²³ Another physician described an advance directive which accepted blood transfusions, but rejected diagnostic procedures. The physician noted, however, that if the author of the directive developed gastrointestinal bleeding, it would be “...absurd to dissociate the two

¹⁷ [2005] 1 WLR 834 at 839-840.

¹⁸ [2003] 2 FLR 408.

¹⁹ *Ibid* at paragraph 24.

²⁰ British Medical Association “Advance Statements about Medical Treatment – Code of Practice” (2000) at 6. Available at <http://www.bma.org.uk/ap.nsf/content/codeofpractice>.

²¹ *Is it Time for Advance Healthcare Directives?* (The Irish Council for Bioethics 2007) at 23.

²² Dresser “Precommitment: A Misguided Strategy for Securing Death With Dignity” (2003) 81 *Texas Law Review* 1823.

²³ Forrow et al “Advance Directives for Medical Care” (1991) 325 *New England Journal of Medicine* 1255 1255 cited in Dresser *ibid* at 1834.

interventions.” A patient who wanted a swift death would refuse both interventions, whereas a patient who had a desire to live would consent to both. The author had failed to appreciate how his specific choices could conflict with his general treatment preferences.²⁴ These examples highlight the importance of ensuring that patients are sufficiently informed when making advance directives.

3.13 Equally, there are dangers associated with discussing future treatment options. Although the Irish Council for Bioethics recommended that an individual should avail of advice and counselling before drafting an advance care directive, it ultimately advised against making it a prerequisite for a directive to be followed.²⁵ It argued that certain individuals may not wish to take counsel on the matter or might not be able to avail of such advice for personal, financial or other reasons. The argument is also propounded that any decision about treatment can rarely be fully informed due to potential developments in medical science and therefore, any advice is potentially futile. However, this argument is easily rebutted if individuals update their advance care directives to take account of any progress in medical science. A number of concerns were also considered in a study conducted by King's College London on *Advance Directives and AIDS* in 1992, including a fear that patients might feel obliged to make a living will where a form was brought out by an enthusiastic doctor without a direct enquiry from the patient.²⁶ Furthermore, concern was expressed that living wills might replace discussions instead of stimulating them. In other words, a doctor might see a living will as a pretext for not communicating with the patient to confirm his or her wishes, even where the patient was in a position to do so.²⁷

(4) Conclusions

3.14 The Commission concurs with the Irish Council for Bioethics that, in general, advice should be sought prior to the drafting of an advance care directive. Discussions will enable a person to clarify their thoughts on their refusal of treatment. Thus consultation with a medical professional should be encouraged. For financial or other reasons, however, a person may decide not

²⁴ Brett “Limitations of Listing Specific Medical Interventions in Advance Directives” (1991) 266 JAMA 825, 827 cited in Dresser “Precommitment: A Misguided Strategy for Securing Death With Dignity” (2003) 81 *Texas Law Review* 1823 at 1834.

²⁵ *Ibid.*

²⁶ Schlyter *Advance Directives and AIDS* (Centre of Medical Law and Ethics King's College London 1992) at 55.

²⁷ *Ibid.*

to consult with a healthcare professional. Indeed, to require a person to do so might lead to a tick-the-box situation and fail to reflect individual autonomy. However, due to the serious consequences involved in the refusal of life-sustaining medical treatment, the Commission concludes that consultation with the medical professional is necessary to ensure the person truly understands the consequences involved in such a decision.

3.15 *The Commission provisionally recommends that makers of advance care directives should be encouraged to consult with a medical professional when making an advance care directive. In the case of advance care directives refusing life-sustaining medical treatment, the Commission provisionally recommends that medical advice must be obtained for the advance care directive to be valid.*

C Capacity

(1) Introduction

3.16 In *Re T*,²⁸ Lord Donaldson provided that "...[t]he right to decide one's own fate presupposes a capacity to do so."²⁹ As noted previously, at common law, the giving of informed consent is a prerequisite to the carrying out of medical treatment. An element of the concept of informed consent at common law is the requirement that the patient has the necessary capacity to decide whether or not to have the proposed medical treatment. Therefore, it must be an essential requirement of an advance care directive that it was made at a time when the author had capacity to make it. It is the responsibility of the relevant medical practitioner to ensure that a person had the capacity to make the contemplated healthcare decision. This places a heavy onus on them given the grave legal and ethical implications of treatment without consent. Despite this, traditionally, there has been little guidance in Ireland on how capacity in the context of consent to medical treatment should be understood and how it should be assessed.³⁰

(2) Presumption of capacity

3.17 In English law, a presumption exists that an adult has the capacity to make his or her own healthcare decisions.³¹ In *Fitzpatrick v FK*, Laffoy J held

²⁸ [1992] 4 All ER 649.

²⁹ *Ibid* at 661.

³⁰ Law Reform Commission *Report on Vulnerable Adults and the Law* (LRC 82-2006) at paragraph 3.32.

³¹ *Re C (adult: refusal of medical treatment)* [1994] 1 All ER 819 (Fam Div) at 824 per Thorpe J; *Re MB (an adult) (medical treatment)* [1997] 2 FLR 426 (CA) at 437

that in Irish law there is a rebuttable presumption, “that an adult patient has the capacity, that is to say the cognitive ability, to make a decision to refuse medical treatment.”³² The Commission recommended in its *Report on Vulnerable Adults and the Law* that its proposed capacity legislation should set out a rebuttable presumption of capacity to the effect that, unless the contrary is demonstrated, every adult is presumed to be capable of making a decision affecting them.³³

3.18 However, the question is raised whether the presumption in favour of capacity also applies to advance treatment refusals or whether a higher standard of capacity is required where a patient refuses life-sustaining treatment or makes a complex treatment decision?³⁴ This question has never been addressed by English or Irish courts. However, the Ontario Court of Appeal in *Malette v Shulman*³⁵ applied a presumption in favour of competence rather than a presumption in favour of preserving the patient’s life. There, an emergency-room doctor gave a life-saving blood transfusion to an unconscious accident victim who carried a card stating that, as a Jehovah’s Witness, she refused blood transfusions under any circumstances. The physician argued that it was lawful to administer the transfusion because he had no way of knowing whether the patient was competent at the time of signing the card. However, it was held that “there was nothing to give credence to or provide support for the speculative inferences implicit in questions as to...her state of mind” at the time of signing the card.

3.19 The Code of Practice for the English *Mental Capacity Act 2005* notes that healthcare professionals should always start from the assumption that a person who has made an advance decision had capacity to make it, unless they are aware of reasonable grounds to doubt the person had the capacity to make the advance decision at the time they made it. If a healthcare professional is not satisfied that the person had capacity at the time they made the advance decision, they can treat the person without fear of liability.³⁶

per Butler-Sloss LJ. See also section 1(2) of the English *Mental Capacity Act 2005*.

³² [2008] IEHC 104 High Court (Laffoy J) 25 April 2008.

³³ Law Reform Commission *Report on Vulnerable Adults and the Law* (LRC 83-2006) at paragraph 2.39.

³⁴ Michalowski “Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right” (2005) 68(6) *Modern Law Review* 958 at 964.

³⁵ (1990) 67 DLR (4th) 321.

³⁶ *Mental Capacity Act 2005 - Code of Practice* at paragraph 9.8.

(3) Assessing capacity

(a) England and Wales

(i) Common law

3.20 An example of assessing competence in the case of a patient's refusal to consent to treatment and to "project that forward to any anticipated intervention"³⁷ occurred in *Re C*.³⁸ In this case, a 68-year old man with chronic paranoid schizophrenia 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, even though C suffered from the delusion that he was a world famous doctor who had never lost a patient. In determining capacity, he devised a three-stage approach: was the patient able to first, comprehend and retain the information; second, believe it; and third, weigh the information so as to arrive at a choice?³⁹ Although C's general capacity to make a decision had been impaired by schizophrenia, he had understood and retained the relevant information, believed it and had arrived at a clear choice.

3.21 A difference in values should not in itself lead to a finding of incapacity. In *Re B*,⁴⁰ a tetraplegic patient was being kept alive by a ventilator and her physicians felt unable to comply with her request to switch it off. Butler-Sloss P was careful to distinguish between autonomy and mental capacity. She stated:

"If there are difficulties in deciding whether the patient has sufficient mental capacity, particularly if the refusal may have grave consequences for the patient, it is most important that those considering the issue should not confuse the question of mental capacity with the nature of the decision made by the patient, however, grave the consequences. The view of the patient may reflect a difference in values rather than an absence of competence

³⁷ Morgan "Odysseus and the Binding Directive: Only a Cautionary Tale?" (1994) 14 *Legal Studies* 411 at 427.

³⁸ [1994] 1 All ER 819.

³⁹ *Ibid* at 824.

⁴⁰ [2002] 2 All ER 449. See also Morgan and Veitch "Being Ms B: B, Autonomy and the Nature of Legal Regulation" (2004) 26 *Sydney Law Review* 107 who argue that there are a number of problems associated with this legal attempt to distinguish between mental capacity and autonomy.

and the assessment of capacity should be approached with this firmly in mind.”⁴¹

The Court held that Ms B possessed the requisite degree of capacity to make the decision to refuse artificial ventilation. To hold otherwise would be to create a “serious danger...of a benevolent paternalism which does not embrace recognition of the personal autonomy” of the patient.⁴²

3.22 However, in *NHS Trust v T*⁴³ the English High Court held that a patient lacked the capacity to refuse a blood transfusion. She had completed an advance directive refusing blood transfusions on the basis that her blood was “carrying evil.” Her assertion was held to be a misconception of reality stemming from a borderline personality disorder. Applying Thorpe J’s test in *Re C*, the court held that Ms T was unable to use and weigh the relevant information and thus the competing factors in the process of arriving at her decision to refuse a blood transfusion.

(ii) Mental Capacity Act 2005

3.23 The English *Mental Capacity Act 2005* requires that an individual must have capacity at the time of making the advance decision.⁴⁴ However, there is no provision in the Act that requires a formal assessment of competency for an advance directive to be valid. The Code of Practice made under the 2005 Act recommends that it may be “helpful” to get evidence of a person’s capacity to make the advance decision, especially if there is a possibility that the advance decision may be challenged in the future.⁴⁵

(b) Ireland

(i) Law Reform Commission recommendations

3.24 In its 2006 *Report on Vulnerable Adults and the Law*, the Commission recommended that capacity to make healthcare decisions should be assessed on the basis of the proposed statutory functional test of capacity, whereby an adult’s legal capacity is assessed in relation to the particular decision made, at the time it is to be made.⁴⁶ The Commission recommended

⁴¹ [2002] 2 All ER 449 at 474.

⁴² *Ibid* at 472.

⁴³ [2005] 1 All ER 387.

⁴⁴ Section 24(1) of the *Mental Capacity Act 2005*.

⁴⁵ *Mental Capacity Act 2005 – Code of Practice* at paragraph 9.7.

⁴⁶ Law Reform Commission *Report on Vulnerable Adults and the Law* (LRC 83-2006) at paragraph 3.23. The Government’s *Scheme of Mental Capacity Bill*

that a person will not be regarded as lacking capacity simply on the basis of making a decision which appears unwise.⁴⁷ It also recommended that the proposed mental capacity legislation make provision for the Minister of Health to appoint a Working Group on Capacity to Make Healthcare Decisions comprising representatives of professional bodies in the healthcare sector, healthcare professionals and lay persons. The role of the Working Group would be to formulate codes of practice for healthcare professionals in relation to capacity and decision-making in the healthcare arena. The subject matter of such codes would include (but not be limited to) the assessment of capacity and the circumstances in which urgent treatment can be carried out without the consent of the adult concerned.⁴⁸

(ii) *Fitzpatrick v FK*

3.25 In the High Court decision of *Fitzpatrick v FK*⁴⁹ Laffoy J noted that an Irish court had never had to consider how capacity to refuse consent to medical treatment on the part of an adult who is mentally competent should be assessed. The case involved a pregnant woman who was a member of the Jehovah's Witness Church. Immediately after giving birth, she was informed that she required a blood transfusion. She refused the transfusion but, on foot of an application by the hospital, the High Court granted an interim injunction authorising a transfusion. The case returned to the High Court before Laffoy J where she considered whether the transfusion was lawfully given.

3.26 This issue gave rise to two questions. The first was whether Ms K had given a legally valid refusal of treatment. In order for a refusal of treatment to be valid, it must be based on the appropriate treatment information, be voluntary,⁵⁰ and made by a person with the necessary capacity. The answer in Ms K's case turned on the capacity question. The second question was if Ms K had capacity, was the court entitled to have regard to her baby son's

2008, published in September 2008¹ proposes to implement these recommendations.

⁴⁷ Law Reform Commission *Report on Vulnerable Adults and the Law* (LRC 83-2006) at paragraph 3.23 at paragraph 2.47. The Government's *Scheme of Mental Capacity Bill 2008* proposes that the Office of the Public Guardian, which the commission recommended in its 2006 Report should be established, will formulate this Code of Practice.

⁴⁸ *Ibid* at paragraph 3.35.

⁴⁹ [2008] IEHC 104 High Court (Laffoy J) 25 April 2008.

⁵⁰ Laffoy J concluded that no issue as to the voluntariness of Ms K's blood transfusion had arisen.

constitutional rights and conclude that his rights outweighed Ms K's constitutional rights to autonomy, self-determination and the free practice of her religion so as to entitle the courts to intervene. The capacity question was to be determined first, because the balancing of rights question would only arise in the event that the court were to find that Ms K's refusal of a blood transfusion was a valid question.

Having undertaken a review of case law from other jurisdictions on capacity, Laffoy J held that the following principles are applicable when determining the capacity question. First, there is a rebuttable presumption that an adult patient has the capacity to make a decision to refuse medical treatment. Second, in determining whether a patient is deprived of capacity to make a decision to refuse medical treatment, 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.”⁵¹

3.27 Third, the three-stage approach to the patient's decision-making process adopted in the English case *Re C* is a “helpful tool” in applying that test. Laffoy J specifically noted that the Law Reform Commission's proposed statutory functional test of capacity was consistent with the *C* case test. 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 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 new-born baby, against the availability of a blood transfusion that would preserve her life.

3.28 Fourth, with regard to the treatment information by reference to which the patient's capacity is to be assessed, she held that 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.”

⁵¹ Citing Lord Donaldson in *Re T (refusal of medical treatment)* [1992] 4 All ER 649.

She 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. Fifth, a distinction was 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.

3.29 Sixth, 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)*⁵² 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.

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.

(iii) Medical Council guidelines

3.30 The Medical Council's ethical guidelines contain some very general guidance on capacity issues. The guidelines simply require an assessment of competence to be carried out in conjunction with a senior colleague.⁵³

3.31 In the concluding section of her judgment, entitled 'Guidance for the Future', Laffoy J noted the "inordinate amount of court time" that the issue had raised, and the amount of time that clinicians and medical personnel had spent in court that would have been "more usefully deployed elsewhere." Therefore, she observed that it would be helpful if:

"[T]he Medical Council Guidelines specifically addressed how capacity to give a valid refusal to medical treatment is to be assessed and, given the inevitability that it will arise in the future, the issues

⁵² [1996] 2 IR 79.

⁵³ Irish Medical Council *A Guide to Ethical Conduct and Behaviour* (6th ed 2004) at paragraph 17.1.

which may arise relating to the giving effect to advance directives to refuse medical treatment.”

(c) Australia

3.32 In Queensland, a rather confusing statutory situation exists, whereby two provisions appear to govern the situation relating to capacity. First, Schedule 3 of the Queensland *Powers of Attorney Act 1998* states that a person is regarded as having capacity if he or she is capable of understanding the nature and effects of decisions, can freely and voluntarily make decisions and can communicate the decision in some way. Under 42 of the 1998 Act, an adult can only make an advance directive if he or she understands the following matters:

- i) “the nature and likely effects of each direction in the advance health directive;
- ii) a direction operates only while the principal has impaired capacity for the matter covered by the direction;
- iii) the principal may revoke a direction at any time the principal has capacity for the matter covered by the direction;
- iv) at any time the principal is not capable of revoking a direction, the principal is unable to effectively oversee the implementation of the direction.”

The Queensland 1998 Act does not clarify how the two provisions interrelate. Willmott submits that a possible interpretation is that section 42 sets out a non-exhaustive list of matters that an adult must be able to understand in order to satisfy the Schedule 3 test of ‘capacity’.⁵⁴ In order to be enforceable, an advance health directive must also include a certificate that is signed and dated by a doctor attesting to the fact that the maker had the necessary capacity to complete the document at the time of making it.⁵⁵

(d) Conclusions

3.33 In the wake of Laffoy’s J comments in *Fitzpatrick v FK*, it is clear that guidance on the issue of capacity is required for healthcare decisions. Such guidance could come from the Commission’s proposed Working Group on

⁵⁴ Willmott “Advance Directives to Withhold Life-Sustaining Medical Treatment: Eroding Autonomy Through Statutory Reform” (2007) 10(2) *Flinders Journal of Law Reform* 287 at 291.

⁵⁵ Section 44(6) of the *Powers of Attorney Act 1998* (Qld).

Capacity to Make Healthcare Decisions.⁵⁶ The Commission reiterates its position that there is a rebuttable presumption of capacity whereby an adult is deemed capable of making a decision affecting them.⁵⁷ The Commission recommends that this presumption includes advance refusals of treatment.

3.34 *The Commission provisionally recommends that there is a rebuttable presumption of capacity in favour of the maker of an advance care directive.*

3.35 *The Commission provisionally recommends that the capacity to refuse medical treatment should be assessed on the functional test of capacity. The Commission also provisionally recommends that statutory codes of practice be formulated to guide healthcare professionals when assessing the capacity of an individual.*

D Age

(a) Introduction

3.36 At what age should a child be considered competent to refuse consent to treatment? Whilst an adult's right to refuse medical treatment is constitutionally recognised in Ireland, the right of mature minors to refuse medical treatment has never been judicially considered.

(b) Statutory provisions

3.37 In Ireland, the general statutory position is that a person aged 18 or over, having reached the age of majority, may consent to or refuse all forms of healthcare. *Age of Majority Act 1985*⁵⁸ However, section 23(1) of the *Non-Fatal Offences Against the Person Act 1997* more specifically states that:

“The consent of a minor who has obtained the age of 16 years to any surgical, medical or dental treatment, which, in the absence of consent, would constitute a trespass to his or her person, shall be as effective as it would be if he or she were of full age; and where a minor has by virtue of this section given an effective consent to any

⁵⁶ Law Reform Commission *Report on Vulnerable Adults and the Law* (LRC 83-2006) at paragraph 3.35. The Government's *Scheme of Mental Capacity Bill 2008* proposes that the Office of the Public Guardian, which the commission recommended in its 2006 Report should be established, will formulate this Code of Practice.

⁵⁷ *Ibid* at 2.39.

⁵⁸ Section 2(1) of the *Age of Majority Act 1985*. See also Tomkin and Hanafin *Irish Medical Law* (Round Hall Press 1995) at 37-44.

treatment it shall not be necessary to obtain any consent for it from his or her parent or guardian.”

3.38 The interpretation of section 23(1) is problematic. Donnelly has identified a number of problems: first, section 23(1) is unclear with regard to the legal standing of a refusal of treatment by an individual aged over 16 years, but under 18 years of age; second, there is no reference to refusal of treatment and it is unclear whether this is implied;⁵⁹ third, section 23(1) does not specifically prohibit individuals under 16 years of age from giving a legal consent to treatment. McMahon and Binchy argue that if section 23(1) were viewed in isolation, the *inclusio unius est exclusio alterius* rule of construction might denote a legislative intent that 16 should be the minimum age for a lawful consent by a minor.⁶⁰ However, section 23(3) states:

“Nothing in this section shall be construed as making ineffective any consent which would have been effective if this section had not been enacted.”

3.39 Therefore, McMahon and Binchy submit that that it appears that the Oireachtas decided to leave open the question whether a minor under 16 has the capacity in any circumstances to consent, without reference to the minor’s parents or guardians. In any event, clarity is required. As Donnelly notes:

“While each doctor’s decision will depend on his view of the circumstances at hand, he is hampered in reaching this decision by the absence of clarity in relation to the legal framework that binds him.”⁶¹

(c) *The ‘mature minor’: capacity of children under 16 to consent to treatment*

3.40 In England and Wales, an almost identical provision to section 23 of the 1997 Act applies. Section 8 of the *Family Law Reform Act 1969* provides that:

“The consent of a minor who has attained the age of sixteen years to any surgical, medical or dental treatment, which in the absence of consent, would constitute a trespass to his person, shall be as

⁵⁹ Donnelly *Consent: Bridging the Gap between Doctor and Patient* (Cork University Press 2002) at 48.

⁶⁰ Mc Mahon and Binchy *Law of Torts* (3rd ed Butterworths 2000) at paragraph 22.81.

⁶¹ Donnelly *Consent: Bridging the Gap between Doctor and Patient* (Cork University Press 2002) at 50.

effective as it would be if he were of full age; and where a minor has by virtue of this section given an effective consent to any treatment it shall not be necessary to obtain any consent for it from his parent or guardian.”

3.41 Similarly, there is no explicit prohibition regarding individuals under the age of 16. Section 8 of the *Family Law Reform Act 1969* was interpreted in the watershed decision of *Gillick v West Norfolk and Wisbech AHA*.⁶² There, a circular had been issued by the Department of Health and Social Security. The circular stated that if a girl under 16 years of age requested contraceptives, a doctor would not be acting unlawfully in providing them in order to protect the girl against the harmful effects of sexual intercourse. It also stated that although the doctor should seek the involvement of the girl's parents, contraceptives could be provided in exceptional circumstances without parental consent. The plaintiff, who had five daughters under the age of 16, sought an assurance from her local Area Health Authority that her daughters would not be given contraceptive advice or treatment without her prior consent. The defendant Health Authority refused to give such an assurance, and the plaintiff sought a declaration from the court that the advice contained in the circular was unlawful and in breach of her parental rights. In finding for the defendants, the House of Lords recognised that:

“... as a matter of law the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed. It will be a question of fact whether a child seeking advice has sufficient understanding of what is involved to give a consent valid in law.”⁶³

3.42 Therefore, an individual assessment of the maturity of the patient must be carried out in each case, evaluating whether the patient understands the nature of the advice being given and whether the patient has sufficient

⁶² [1986] AC 112. See Donnelly “Capacity of Minors to Consent to Medical and Contraceptive Treatment” (1995) 1 *Medico-Legal Journal of Ireland* 18; Laurie “The Autonomy of Others: Reflections on the Rise and Rise and Rise of Patient Choice in Contemporary Medical Law” in McLean (ed) *First Do No Harm* (Ashgate 2006) 131 at 137-142. For a thorough discussion on the age of maturity in general, see Madden *Medicine, Ethics & the Law* (Tottel Publishing 2002) at paragraphs 10.114-10.176.

⁶³ [1986] AC 112 at 188 per Lord Scarman.

maturity to understand what is involved. The term *Gillick*-competent is now part of “medico-legal lore”.⁶⁴

3.43 The Scottish legislature appears to have taken *Gillick* into consideration when drafting the *Age of Legal Capacity (Scotland) Act 1991*.⁶⁵ Section 2(4) specifically makes provision for medical treatment for those under the age of 16:

“A person under the age of 16 years shall have legal capacity to consent on his own behalf to any surgical, medical or dental procedure or treatment where, in the opinion of a qualified medical practitioner attending him, he is capable of understanding the nature and possible consequences of the procedure or treatment.”

(d) *The ‘mature minor’: capacity of children under 16 to refuse treatment*

3.44 The *Age of Legal Capacity (Scotland) Act 1991* also suffers from the same deficiency as section 8 of the English *Family Law Reform Act 1969* and section 23(1) of the *Non-Fatal Offences Against the Person Act 1997* in that there is no express provision for refusal of treatment. Nor was the issue specifically addressed by the House of Lords in the *Gillick* decision.

3.45 The problematic question of whether a mature minor could refuse as well as consent to treatment was addressed in the English case of *Re R (a minor) (wardship: medical treatment)*.⁶⁶ A local authority began wardship proceedings seeking permission from the court to give a 15 year old girl anti-psychotic drugs without her permission. The English Court of Appeal concluded that *Gillick* had no application in the present case, as it was a wardship case which had to be determined in accordance with the best interests of the ward. Although R was incompetent to make the relevant medical decision because of her fluctuating medical condition, the Court did engage in a discussion of the power of a competent mature minor to refuse treatment. All three judges accepted that the court has the power to override the refusal of a competent child.⁶⁷ However, only Lord Donaldson MR commented (albeit *obiter*) on the issue of conflicting wishes of parents and child. He observed that a *Gillick*

⁶⁴ Mason and Laurie *Mason and McCall Smith’s Law and Medical Ethics* (7th ed Oxford University Press 2006) at paragraph 10.27.

⁶⁵ See Elliston “If You Know What’s Good for You: Refusal of Consent to Medical Treatment by Children” in McLean (ed) *Contemporary Issues in Law, Medicine and Ethics* (Dartmouth 1996) 29 at 49-51.

⁶⁶ [1991] 4 All ER 177.

⁶⁷ Lord Donaldson MR, Staughton LJ, Farquharson LJ.

competent child can consent to treatment, but if the child refuses treatment, consent can be given by someone who has parental rights or responsibilities.⁶⁸

3.46 A number of issues were left unresolved by *Re R* which were at issue before the Court of Appeal in 1992 in *Re W (a minor) (medical treatment)*.⁶⁹ *W* was sixteen years old. Therefore, the *Family Law Reform Act 1969* applied in this case, whereas it did not apply in either *Gillick* or *Re R*. Thus, the following question had to be addressed: does a minor who has attained the age of 16, but who is still under the age of majority have an absolute right to refuse medical treatment, such that section 8 of the 1969 Act does not apply?⁷⁰ In *Re W*, the Court of Appeal granted an application by a local authority for permission to treat a 16 year old girl suffering from anorexia against her wishes. Balcombe LJ observed that:

“Undoubtedly, the philosophy behind section 8 of the 1969 Act, as well as behind the decision of the House of Lords in *Gillick*'s case is that, as children approach the age of majority, they are increasingly able to taken their own decisions concerning their medical treatment and an ability to refuse medical treatment...”⁷¹

However, the court noted that although section 8 of the *Family Law Reform Act 1969* explicitly referred to the right of a minor who has attained the age of 16 to consent to treatment, it was silent as to whether a right to refuse medical treatment existed. It accepted that a child over the age of 16, as well as a *Gillick* competent child, has a right to refuse as well as consent to treatment. However, neither section 8 of the 1969 Act nor the common law, as interpreted by *Gillick*'s case, conferred an *absolute* right to refuse treatment on either category of minor. If the court's powers were to be meaningful:

“...there must come a point at which the court, while not disregarding the child's wishes, can override them in the child's own best interests, objectively considered. Clearly, such a point will have come if the child is seeking to refuse treatment in circumstances which will in any probability lead to the death of the child or to severe permanent injury.”⁷²

3.47 Elliston has argued that it is illogical to draw a distinction between the ability to consent to treatment and the ability to refuse treatment. Rather, “the

⁶⁸ *Re R (a minor) (wardship: medical treatment)* [1991] 4 All ER 177 at 186.

⁶⁹ [1992] 4 All ER 627.

⁷⁰ Kennedy and Grubb *Medical Law* (3rd ed Butterworths 2000) at 975.

⁷¹ *Re W (a minor) (medical treatment)* [1992] 4 All ER 627 at 643 per Balcombe LJ.

⁷² *Ibid.*

right to say yes must carry with it the right to say no.”⁷³ Whilst conceding that consent “involves the acceptance of an experienced view, refusal rejects that experience – and does so from a position of limited understanding”,⁷⁴ she maintains that the same argument applies to adults, as most patients will know less about the treatment of their disease than their doctor. Mason, however, takes the opposite view:

“...a refusal of medical treatment may close down the options – and this may be regretted later in that the chance to consent has now passed. The implications of refusal may, therefore, be more serious and, on those grounds refusal of treatment may require greater understanding than does acceptance. A level of comprehension sufficient to justify refusal of certain treatment includes one to accept treatment but the reverse does not hold; the two conditions cannot be regarded as being on a par.”⁷⁵

(e) Other jurisdictions

3.48 Section 24 of the English *Mental Capacity Act 2005* incorporates the recommendation of the Law Commission of England and Wales that a person may make an advance decision “after he has reached 18”.⁷⁶ Similarly, in Denmark, the *Health Act 2005* states that any person over the age of 18 and not under guardianship may make a living will.⁷⁷

3.49 Canadian states vary in the minimum age required to make a valid directive. In Alberta, a person must be over 18.⁷⁸ In Saskatchewan and

⁷³ Elliston “If You Know What’s Good for You: Refusal of Consent to Medical Treatment by Children” in McLean (ed) *Contemporary Issues in Law, Medicine and Ethics* (Dartmouth 1996) 29 at 34 citing Norrie ““The Age of Legal Capacity (Scotland) Act 1991” (1991) 36 *Journal of the Law Society of Scotland* 111. See also Derish and Vanden Heuvel “Mature Minors Should Have the Right to Refuse Life-Sustaining Medical Treatment” (2000) 28 *Journal of Law, Medicine and Ethics* 109.

⁷⁴ Elliston “If You Know What’s Good for You: Refusal of Consent to Medical Treatment by Children” in McLean (ed) *Contemporary Issues in Law, Medicine and Ethics* (Dartmouth 1996) 29 at 34 citing Mason and McCall Smith *Law and Medical Ethics* (4th ed London: Butterworths 1994) at 229.

⁷⁵ Mason and Laurie *Mason and McCall Smith’s Law and Medical Ethics* (7th ed Oxford University Press 2006) at paragraph 10.52.

⁷⁶ Section 24(1) of the *Mental Capacity Act 2005*.

⁷⁷ Section 1 of §26 of the *Health Act 2005*.

⁷⁸ Section 5(1) of the *Personal Directives Act, S.A. 1996 c. P-4.03*.

Manitoba, a person must be over 16.⁷⁹ Newfoundland and Labrador does not have a minimum age requirement.

3.50 In Singapore, a person must have attained the age of 21 in order to make an advance medical directive.⁸⁰

(f) Conclusion

3.51 While the age for consenting to medical treatment is 16, the Commission notes there is a difference between refusing and consenting to medical treatment. A refusal of life-sustaining medical treatment has very serious consequences. Has a person as young as 16 the maturity and capability to make such a decision? In view of the complex issues that arise in this respect, the Commission wishes to invite submissions on this issue.

3.52 *The Commission invites submissions on the age a person must be before they can make a valid advance care directive.*

⁷⁹ Section 2(1)(c) of *The Health Care Directives and Substitute Health Care Decision Makers Act*, S.S. 1997, c. H-001; section 5 of the *Health Care Directives Act*, C.C.S.M. 1993, c. H-27.

⁸⁰ Section 3 of the *Advance Medical Directive Act 1996* (Singapore).

CHAPTER 4 **FORMALITIES FOR ADVANCE CARE DIRECTIVES**

A Introduction

4.01 In this Chapter, a number of formalities concerning advance care directives are considered by the Commission. Part B discusses whether an advance care directive should be in writing. Part C discusses safeguards regarding advance care directives that refuse life-sustaining treatment. Part D considers whether advance care directives should be witnessed, and if so, whether certain parties should be excluded from acting as witnesses. Part E examines whether advance care directives should be in a prescribed form. Part F discusses “valid” and “applicable” safeguards that the English *Mental Capacity Act 2005* has imposed. Part G discusses when an advance care directive should be activated, otherwise known as the ‘triggering event’. Part H discusses the potential problems that arise first, when a patient attempts to revoke an advance care directive when incompetent and second, when a patient has changed his or her mind, but has failed to actually revoke the directive. Part I debates whether advance care directives should be subject to regular review, and whether they should lapse after a specified number of years unless reviewed. Part J considers methods for storing advance care directives.

B Oral and Written Advance Care Directives

4.02 The English Court of Appeal judgment in *Re T*¹ noted that an anticipatory decision may take a number of forms, including “a hospital’s standard form of refusal, a ‘no blood’ card carried by a Jehovah’s Witness, or a spoken refusal repeated to the patient’s doctor, nurse and midwife, in the presence of family members.”² Mills also stated that an advance care directive could be written, could be recorded in a patient’s notes or could be made orally.³

¹ [1992] 4 All ER 649.

² *Ibid.*

³ Mills *Clinical Practice and the Law* (2nd ed Tottel Publishing, 2007) at paragraph 12.35

4.03 The decision in *W Healthcare NHS Trust v H*⁴ indicates, however, that it may be difficult to clearly establish an oral advance decision. The English Court of Appeal was asked to consider whether conversations conducted some ten years earlier were sufficient to constitute an advance directive refusing the reinsertion of a percutaneous gastrostomy tube (Peg tube). The patient was a 59-year old woman suffering from multiple sclerosis requiring 24-hour care to enable her to survive. She was “conscious but not more than that” and she was unable to recognise even those who were closest to her in her family.⁵ Evidence was put forward that she had previously said to her daughter, “I don’t want to be kept alive by machines”, and to a close friend that she did not want to be a burden to her daughters or kept alive if she could no longer recognise them. Despite this, Brooke LJ stated:

“I am of the clear view that...there was not an advance directive which was sufficiently clear to amount to a direction that she preferred to be deprived of food and drink for a period of time which would lead to her death in all circumstances. There is no evidence that she was aware of the nature of this choice, or the unpleasantness or otherwise of death by starvation and it would be departing from established principles of English law if one was to hold that there was an advance directive which was established and relevant in the circumstances in the present case, despite the very strong expression of her wishes which came through in the evidence.”⁶

It is clear, therefore, that while it should be permissible for persons to express themselves in verbal form, this may give rise to difficulties of scope and application.

4.04 In 1994, one writer noted that although there was no reason in principle to disregard oral advance care directives, “it is common to assume that advance declarations should be required to be made in writing”.⁷ The writer added: “This has significant practical advantages. It provides concrete evidence of the patient’s wishes which would reduce the likelihood of disputes. It will also overcome the weaknesses of memory of those in whom the patient confided.

⁴ [2005] 1 WLR 834.

⁵ *Ibid* at 834.

⁶ *Ibid* at 840.

⁷ Montgomery “Power Over Death: The Final Sting” in Lee and Morgan (eds) *Death Rites: Law and Ethics and the End of Life* (Routledge 1994) 37 at 43.

This leaves less scope for the existence of directions to be forgotten or for mistakes as to their terms.”⁸

4.05 In his 1969 proposal for advance care directives, Kutner proposed that the living will should be notarised and attested to by at least two witnesses who would affirm that the maker was of sound mind and acted of his own free will.⁹ There are a number of advantages associated with imposing formal requirements. First, formalities of execution can provide reliable and permanent evidence of the maker’s intentions. Second, they can minimise the effect of undue influence and fraud. Third, they can ensure that the maker of the advance care directive has capacity and is well informed as to the significant consequences of a decision. On the other hand, formal requirements may discourage the public from drafting advance care directives due to inconvenience and cost.

(1) *Mental Capacity Act 2005*

4.06 In 1993, the Law Commission for England and Wales noted that it would be reluctant to deprive an advance decision of validity merely because it was not made in a particular form.¹⁰

4.07 The English *Mental Capacity Act 2005* appears to have adopted this approach by providing that an advance decision may be either written or oral. There is no set format for oral advance decisions. The Code of Practice for the 2005 Act notes that this is because “they will vary depending on a person’s wishes and situation.”¹¹ However, it recommends that, in order to prevent future confusion, “where possible, healthcare professionals should record a verbal advance decision to refuse treatment in a person’s healthcare record.”¹² This record should include:

- “a note that the decision should apply if the person lacks capacity to make treatment decisions in the future;

⁸ Montgomery “Power Over Death: The Final Sting” in Lee and Morgan (eds) *Death Rites: Law and Ethics and the End of Life* (Routledge 1994) 37 at 43.

⁹ Kutner “Due Process of Euthanasia: The Living Will, A Proposal” (1969) 44 *Indiana Law Journal* 539 at 551.

¹⁰ The Law Commission for England and Wales *Consultation Paper on Mentally Incapacitated Adults and Decision-Making, Medical Treatment and Research* (No 129 1993) at paragraph 5.29.

¹¹ *Mental Capacity Act 2005 - Code of Practice* at paragraph 9.22

¹² *Ibid* at paragraph 9.23

- a clear note of the decision, the treatment to be refused and the circumstances in which the decision will apply;
- details of someone who was present when the oral advance decision was recorded and the role in which they were present (for example, healthcare professional or family member); and
- whether they heard the decision, took part in it or are just aware that it exists.”¹³

4.08 The English 2005 Act does not set out formal requirements if the advance care directive is in writing. However, the Code of Practice for the English notes that it is “helpful” to include the following information in a written advance directive:

- “full details of the person making the advance decision, including date of birth, home address and any distinguishing features (in case healthcare professionals need to identify an unconscious person, for example);
- the name and address of the person’s GP and whether they have a copy of the document;
- a statement that the document should be used if the person ever lacks capacity to make treatment decisions;
- a clear statement of the decision, the treatment to be refused and the circumstances in which the decision will apply;
- the date the document was written (or reviewed);
- the person’s signature (or the signature of someone the person has asked to sign on their behalf and in their presence);
- the signature of the person witnessing the signature, if there is one (or a statement directing somebody to sign on the person’s behalf).”¹⁴

4.09 While the *Mental Capacity Act 2005* provides for both oral and written advance care directive, it has been suggested that “this apparent flexibility is somewhat illusory”.¹⁵ Bartlett argues that regardless of what the 2005 Act may say “a practitioner or a court will be hesitant to rely on a refusal without clear evidence that it was meant to be taken seriously”.¹⁶ Bartlett argues that while a

¹³ *Mental Capacity Act 2005 - Code of Practice* at paragraph 9.23.

¹⁴ *Mental Capacity Act 2005 – Code of Practice* at paragraph 9.19.

¹⁵ Bartlett *Blackstone’s Guide to the Mental Capacity Act 2005*, 2nd ed. (Oxford, 2008) at paragraph 3.116.

¹⁶ *Ibid.*

record of the oral advance care directive on a patient's records will help, a written advance care directive is the only way to ensure that it will be followed.

(2) Other jurisdictions

4.10 A small minority of states in the United States allow oral advance directives. This involves a declaration of a patient's treatment to his doctor, who then makes an official addition to the patient's medical record.¹⁷

4.11 In the Australian Capital Territory, oral directives are permitted.¹⁸ It must, however, be witnessed by two health professionals, one of whom must be a doctor.¹⁹

(3) Conclusions

4.12 The Commission notes the value of written advance care directives in promoting clarity. However the Commission also notes that it may not always be possible to prepare a written advance care directive. An oral advance care directive allows for flexibility. The Commission concludes that, subject to its views on advance care directives concerning life-sustaining treatment, discussed in Part C below, it should be permissible to recognise the validity of oral advance care directives. The Commission recognises that this will involve issues of interpretation in practice and will explore these issues in the context of the consultation process leading to its final recommendations in this area.

4.13 *The Commission provisionally recommends that both oral and written advance care directives are valid.*

C Advance care directives to refuse life-sustaining treatment

(1) Mental Capacity Act 2005

4.14 Section 25 of the English *Mental Capacity Act 2005* imposes specific conditions regarding advance decisions refusing life sustaining treatment. Life-sustaining treatment is defined rather broadly as "treatment which in the view of a person providing health care for the person concerned is necessary to sustain life."²⁰ In addition to being valid and applicable,²¹ the advance decision must be:

- in writing;

¹⁷ For example, Maryland: MD Code Ann Health-Gen § 5-602d (West 2004).

¹⁸ Section 7 (2) *Medical Treatment (Health Directions) Act 2006* (ACT).

¹⁹ *Ibid* at Section 9 (1).

²⁰ Section 4(1) of the *Mental Capacity Act 2005*.

²¹ See paragraphs 4.38-4.62 below.

- signed by the maker of the advance decision or by another person in the maker's presence and by the maker's direction, and that signature is made or acknowledged in the presence of a witness who signs or acknowledges his/her signature in the presence of the maker of the decision;
- verified by a statement by the maker to the effect that it is to apply to that treatment even if his/her life is at risk.

4.15 The common law had no such formalities in these circumstances. Unlike the provisions relating to validly executed enduring powers of attorney, there are no transitional provisions for advance refusals of life-sustaining treatment. If an individual made an advance refusal of life-sustaining treatment prior to the enactment of the *Mental Capacity Act 2005*, they must execute a new decision that complies with section 25 of the Act.

4.16 Where there are doubts as to the validity and applicability of an advance decision, section 26(5) of the English 2005 Act provides that life-sustaining treatment may be given to the maker and any other act may be done to prevent a serious deterioration of the maker's condition, while a decision is sought from the court. A potential danger associated with section 26(5) however, is that a treatment provider may seek a court declaration, not because of any genuine reservations regarding the validity and applicability of an advance decision, but rather to avail of life-sustaining treatment pending the court decision. However, according to section 26(2), a treatment provider does not incur liability for carrying out treatment, unless at the time, he is "satisfied" that an advance decision exists which is valid and applicable to the treatment. Therefore, potential liability could ensue.²²

(2) Queensland

4.17 In Queensland, significantly greater restrictions are imposed where a direction in an advance health directive relates to the withholding or withdrawal of a life-sustaining measure. The definition of a "life-sustaining measure" is defined in a more specific manner than in the English *Mental Capacity Act 2005*. Section 5A of the Queensland *Powers of Attorney Act 1988* states that:

- (1) "A 'life-sustaining measure' is 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.

²² Bartlett *Blackstone's Guide to the Mental Capacity Act 2005* (Oxford University Press 2005) at paragraph 3.26.

- (2) Without limiting subsection (1), each of the following is a ‘life-sustaining measure’ –
 - (a) cardiopulmonary resuscitation;
 - (b) assisted ventilation;
 - (c) artificial nutrition and hydration.
- (3) A blood transfusion is not a “life-sustaining measure”.

4.18 The Queensland 1998 Act also states that two or three conditions must be met (depending on the circumstances). First, the adult’s health must be in decline and the adult must:

- have a terminal illness, or a condition that is incurable or irreversible, from which the adult may reasonably be expected to die within one year; or
- be in a persistent vegetative state;
- be permanently unconscious; or
- have an illness or injury of such severity that there is no reasonable prospect that the adult will recover to an extent that life-sustaining measures will not be needed.²³

4.19 Second, the advance health directive can only apply if the adult has no reasonable prospect of regaining capacity for health matters.²⁴ The third condition will only apply if the advance health directive directs that artificial nutrition and hydration is to be withheld or withdrawn. The commencement or continuation of artificial nutrition and hydration must be inconsistent with good medical practice in order for the directive to be valid.²⁵

(3) Artificial Nutrition and Hydration (ANH)

4.20 Withdrawal of artificial nutrition and hydration (ANH) will usually lead to death, but can it be described as life-sustaining medical treatment? While it can be argued that the removal of ANH simply allows nature to take its course, Power points out that many people require assistance in their feeding,²⁶

²³ Section 36(2)(a) of the *Powers of Attorney Act 1998* (Qld).

²⁴ Section 36(2)(c) of the *Powers of Attorney Act 1998* (Qld).

²⁵ Section 36(2)(b) of the *Powers of Attorney Act 1998* (Qld).

²⁶ Power, “Bioethics and the End of Life” (2008) *Bar Review* 19 at 21.

including babies, the elderly and people with spinal cord injuries. If the carer for these people fails to feed this person, criminal liability could arise.²⁷

4.21 This issue arose in *Re a Ward of Court (No 2)*.²⁸ Blayney J stated that “normal food and drink could never be categorised as medical treatment”.²⁹ Hamilton CJ did find that artificial feeding was “medical treatment”.³⁰ However he went on to state that the withdrawal of artificial nutrition would not be the cause of death, it would be the injuries originally sustained which had caused the coma.³¹ While the practical implications of the withdrawal of ANH was death, Hamilton CJ appears to suggest that ANH is not life-sustaining treatment.

(4) Conclusions

4.22 The Commission recognises the serious implications involved in refusing life-sustaining medical treatment. The Commission appreciates, however, that the scope of this area requires further consideration. In light of the discussion of how this area has been treated in other jurisdictions, in the case of life sustaining treatment, the Commission provisionally recommends that only written advance care directives are valid. The Commission welcomes submissions on the definition of life-sustaining medical treatment and on whether artificial nutrition and hydration is life-sustaining medical treatment.

4.23 *In the case of life-sustaining treatment, the Commission provisionally recommends that only written advance care directives are valid. The Commission welcomes submissions on the definition of life-sustaining medical treatment and on whether artificial nutrition and hydration is life-sustaining medical treatment.*

D Witnesses

4.24 Although the Law Commission of England and Wales recommended that patients should express any advance refusals of treatment in writing, to sign the document and to have their signature witnessed,³² the English *Mental Capacity Act 2005* does not incorporate such formalities. It is only when an advance decision refuses life-sustaining treatment that it must be signed by the

²⁷ Power, “Bioethics and the End of Life” (2008) *Bar Review* 19 at 22.

²⁸ [1996] IR 79.

²⁹ *Ibid* at 144.

³⁰ *Ibid* at 126.

³¹ *Ibid* at 128.

³² Law Commission of England and Wales *Report on Mental Incapacity* (No 231 1995) at paragraph 5.30.

maker of the advance decision or by another person in the maker's presence and by the maker's direction, and that signature is made or acknowledged in the presence of a witness who signs or acknowledges his or her signature in the presence of the maker of the decision.³³

4.25 Witnessing requirements exist in all Australian jurisdictions.³⁴ However, the requirements vary across jurisdictions. For example, in the Australian Capital Territory and the Northern Territory, witnesses need only attest to the fact that the adult signed the directive.³⁵ However, in Queensland, South Australia and Victoria, a witness must attest to the fact that the adult had the requisite capacity to make the directive.³⁶

(1) Disinterested witness requirement

4.26 In 1988, the English Age Concern Report raised the question as to whether certain persons, such as creditors or potential beneficiaries, should be excluded from witnessing an advance directive. It proposed that at least one witness must be "neither a relative nor a person who would take any part of the estate by will or otherwise on the death of the person involved."³⁷ Whilst the English *Mental Capacity Act 2005* did not adopt this suggestion, it has been adopted in other jurisdictions.

4.27 For example, in North Dakota an advance care directive must either be notarised or signed by two witnesses, at least one of which may not be:

³³ Section 25(5) of the *Mental Capacity Act 2005*.

³⁴ Section 7(b) of the *Medical Treatment Act 1994* (ACT); section 4(1) of the *Natural Death Act 1988* (NT); regulation 2 of the *Natural Death Regulations 1989* (NT); section 44(3)(a)(i) 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(2) schedule 1 of the *Medical Treatment Act 1988* (Vic).

³⁵ Section 7(2)(c)-(d) schedule 1 form 1 of the *Medical Treatment Act 1994* (ACT); section 4(2) of the *Natural Death Act 1988* (NT); regulation 2 of the *Natural Death Regulations 1989* (NT).

³⁶ 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).

³⁷ Kings' College London *The Living Will: Consent to Treatment at the End of Life* (Working Party Report, Age Concern and Centre of Medical Law and Ethics 1988).

“...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.”³⁸

4.28 In other words, at least one of the witnesses listed above must be a ‘disinterested witness’. The rationale behind such a requirement is that it avoids any potential conflict of interest or duress by those who have an interest in the executor’s death. It has been argued, however, that this is a “most pernicious technicality” which has the potential to “wreak havoc on the emerging field of advance directive law.”³⁹

(a) Doctors and other healthcare providers

4.29 Proponents of disqualifying healthcare professionals as witnesses would argue that it ensures that vulnerable patients are protected by eliminating any possible conflict of interest. However, not only does this justification fly in the face of the Hippocratic oath to “do no harm”, but it also disregards the common complaint that doctors disregard the plain instructions of a patient’s advance care directive in their “zeal to cure.”⁴⁰ The United States *Uniform Health Care Decisions Act 1997* chose not to require witnesses for advance directives. In doing so, it was cited for relying “on recordkeeping – entering the advance directive in the patient’s health care records – and conformance with medical ethics as affirmative rules to determine and effectuate genuine intent.”⁴¹

4.30 Conversely, the Hong Kong Law Reform Commission recommended that advance care directives be witnessed by two witnesses, one of whom *must* be a medical practitioner, neither witness having an interest in the estate of the

³⁸ ND Cent Code § 23-06.5-05 (2005)

³⁹ Kusmin “Swing Low, Sweet Chariot: Abandoning the Disinterested Witness Requirement for Advance Directives” (2006) 32 *American Journal of Law, Medicine & Ethics* 93 at 94.

⁴⁰ *Ibid* at 108.

⁴¹ Cited in Kusmin at 109.

person making the advance care directive.⁴² It argued that requiring a medical practitioner to act as a witness would serve a number of purposes. The medical practitioner would be able to assess whether the individual was competent at the time of making the advance care directive and explain the nature and implications of making the advance care directive to the maker. It argued that consistency of practice by witnessing doctors could best be achieved by the Medical Council issuing guidelines.

(b) Heirs and relatives

4.31 The rationale for disqualifying heirs and relatives is to guard against duress and coercion, and appears to be borrowed from the law of wills.⁴³ An individual who takes under the will cannot be regarded as an impartial witness to attest to the circumstances surrounding the execution of the will. However, the difficulty with excluding heirs and relatives from acting as witnesses is that they are likely to be the individuals most familiar with the maker's wishes and values and "most likely to advocate honestly on his behalf."⁴⁴

(2) Conclusion

4.32 While reluctant to impose a list of requirements to satisfy before a written advance care directive is valid, the Commission provisionally recommends that a written advance care directive which refuses life-sustaining medical treatment must be witnessed by at least one person. At first glance a medical professional would be suited for this role as they are in a position to explain the implications of an advance care directive. To impose such a duty, however, would be an undue burden upon the doctor.

4.33 *The Commission provisionally recommends that only a written advance care directive which refuses life-sustaining medical treatment must be witnessed by at least one person.*

⁴² Hong Kong Law Reform Commission *Report on Substitute Decision-Making and Advance Directives in Relation to Medical Treatment* at 170-172.

⁴³ For example, in Ireland, under section 82(1) of the *Succession Act 1965*, if a witness attests the execution of a will and any devise, bequest, estate, interest, gift or appointment of or affecting any property is given or made by the will to that person or his spouse, that gift, so far as it concerns the witness or his spouse, shall be null and void.

⁴⁴ Kusmin "Swing Low, Sweet Chariot: Abandoning the Disinterested Witness Requirement for Advance Directives" (2006) 32 *American Journal of Law, Medicine & Ethics* 93 at 107.

E Prescribed form

4.34 In certain jurisdictions, such as the Australian Northern Territory, an advance care directive must be in a prescribed form.⁴⁵ There are a number of advantages associated with this formality. First, it provides a guide for patients who might otherwise make “medically unsound or legally untenable” requests in which case “the doctor responsible for implementing the living will may be exposed to ethical and legal insecurity.”⁴⁶ Second, if a range of different documents were employed, doctors might find it difficult to adopt a workable practice and simply choose not to pay attention to them.⁴⁷

4.35 The Alberta Law Reform Commission recommended, however, that patients should be free to adopt any form of advance directive:

“To include a recommended form in the legislation might well give the misleading impression that it is the only form (or the preferred form) of healthcare directive, and thus might be adopted regardless of the particular individual’s needs and circumstances. A healthcare directive should be tailored to fit the wishes and needs of the individual, and we would not wish the legislation to imply that there is a ‘boilerplate’ version which can be used in all cases.”⁴⁸

4.36 An advance care directive will differ according to the treatment refused and the circumstances in which it was drafted. Due to the individuality of each advance care directive, one form will not suit all. The Commission recognises, however, that there is a basic amount of information which should be contained in any advance care directive. The information should include, but not be limited to, the name, address, date of birth and GP of the advance care directive author, the treatment to which the author does not wish to consent to and the name and address of the proxy. Because of the scope of circumstances noted, the Commission does not wish to be prescriptive in this respect but notes

⁴⁵ Section 18(1) of the *Natural Death Act 1988* (NT).

⁴⁶ Kings’ College London *The Living Will: Consent to Treatment at the End of Life* (Working Party Report, Age Concern and Centre of Medical Law and Ethics (1988).

⁴⁷ Schlyter *Advance Directives and AIDS* (Centre of Medical Law and Ethics Kings College London 1992) at 70.

⁴⁸ Alberta Law Reform Commission *Report on Advance Directives and Substitute Decision Making in Personal Health Care: A Joint Report of the Alberta Law Reform Institute and the Health Law Institute* (No 64 1993) at 17.

that the Irish Council for Bioethics has published some examples of the different forms that an advance care directive might take.⁴⁹

4.37 *The Commission provisionally recommends that it is not necessary for an advance care directive to be in a prescribed form.*

F Validity and applicability generally

4.38 In the English case *Re T*, Lord Donaldson MR observed that the binding nature of an advance directive is dependent upon “two major ‘ifs’”: if the choice is clearly established and if it is applicable in the circumstances.⁵⁰ Section 25 of the English *Mental Capacity Act 2005* echoes the common law position, containing two important safeguards, namely, that an advance decision must be both valid and applicable to the proposed treatment.

4.39 It is ultimately the responsibility of the healthcare professional who is in charge of the patient’s care to decide whether there is an advance decision which is valid and applicable in the circumstances.⁵¹ In the event of doubt, the Court of Protection can rule on whether an advance decision exists, is valid and is applicable to the treatment proposed.⁵² If the court rules that it is, the decision must be respected. There is no mechanism for the court to overrule a valid and applicable advance decision to refuse treatment.

(1) Valid

4.40 Section 25(2) of the English *Mental Capacity Act 2005* states that an advance decision is not valid if the maker of an advance decision has:

- (a) “withdrawn the decision at a time when he had capacity to do so;
- (b) under a lasting power of attorney created after the advance decision was made, conferred authority on the donee (or, if more than one, any of them) to give or refuse consent to the treatment to which the advance decision relates; or
- (c) done anything else clearly inconsistent with the advance decision remaining his fixed decision.”⁵³

⁴⁹ Irish Council for Bioethics *Is it Time for Advance Care Directives?* (2007) Appendix 4.

⁵⁰ [1992] 4 All ER 649 at 653.

⁵¹ *Mental Capacity Act 2005 - Code of Practice* at paragraph 9.64.

⁵² Section 26(4) of the *Mental Capacity Act 2005*.

⁵³ Section 25(2) of the *Mental Capacity Act 2005*.

4.41 The scope of section 25(2)(c) is “potentially remarkably expansive.”⁵⁴ An illustration of its potential scope can be seen in *HE v A Hospital Trust*,⁵⁵ a case decided before the enactment of the *Mental Capacity Act 2005*. There, a 24-year-old Jehovah’s Witness, who had been born a Muslim, required a life-saving blood transfusion. She had, however, previously written an advance care directive refusing consent to such treatment “in any circumstances.” Her father applied for a court declaration that the administration of a blood transfusion to his daughter was lawful despite the advance care directive. In support of his application, her father stated that his daughter had become engaged to a Muslim and promised him to convert to that faith and no longer attend meetings of the Jehovah’s Witnesses. Furthermore, his daughter had admitted herself to a hospital shortly before her collapse and made no reference to being a Jehovah’s Witness and to having objections to blood transfusions. On the other hand, the advance care directive was only two years old and his daughter had made no attempt to rescind it. Munby J summarised the predicament by 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.”⁵⁶

He held that “the continuing validity and applicability of the advance directive must be clearly established by clear and convincing evidence,” and concluded that the father’s evidence raised “considerable doubt”. In these circumstances, the directive:

“cannot have survived her deliberate, implemented decision to abandon that faith and revert to being a Muslim. When the entire substratum has gone, when the very assumption on which the advance directive was based has been destroyed by subsequent events then...the refusal ceases to be effective.”⁵⁷

⁵⁴ Bartlett *Blackstone’s Guide to the Mental Capacity Act 2005* (Oxford University Press 2005) at paragraph 2.106.

⁵⁵ *HE v A Hospital Trust* [2003] EWHC 1017; [2003] 2 FLR 408.

⁵⁶ *Ibid* at 415.

⁵⁷ *HE v A Hospital Trust* [2003] EWHC 1017; [2003] 2 FLR 408 at 422.

4.42 The case has been criticised on the basis that although there was some evidence that there had been a change in circumstances, the advance care directive remained the most authoritative indication of her wishes.⁵⁸ However, it has also been argued that it is doubtful whether the case would have been decided differently under section 25(2)(c) of the English *Mental Capacity Act 2005*. The woman in the case had merely promised her fiancée that she would convert to the Muslim faith. It is uncertain whether her engagement to a Muslim man in itself can be regarded as “clearly inconsistent” with the patient’s refusal to have blood transfusions administered. Had she converted, the situation might be different.⁵⁹ Nevertheless, it appears that advance refusals of life-sustaining treatment will be upheld only in cases of manifest and unambiguous validity and therefore, authors will have to be vigilant for their views to be respected.⁶⁰

(2) Applicable

4.43 Section 25 of the English *Mental Capacity Act 2005* states that an advance decision is not applicable to the treatment in question if:

- at the material time the maker of the advance decision has capacity to give or refuse consent to it;⁶¹
- that treatment is not the treatment specified in the advance decision,⁶² or
- any circumstances specified in the advance decision are absent;⁶³ or
- there are reasonable grounds for believing that circumstances exist which the maker of the advance decision did not anticipate at the time of the advance decision and which would have affected his decision had he or she anticipated them.⁶⁴

⁵⁸ Mc Lean “Advance Directives and the Rocky Waters of Anticipatory Decision-Making” (2008) 16(1) *Medical Law Review* 1.

⁵⁹ Michalowski “Advance Refusal of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right” (2005) 68(6) *Modern Law Review* 958 at 971-972.

⁶⁰ Bartlett *Blackstone’s Guide to the Mental Capacity Act 2005* (Oxford University Press 2005) at paragraph 2.106.

⁶¹ Section 25(3) of the *Mental Capacity Act 2005*.

⁶² Section 25(4) of the *Mental Capacity Act 2005*.

⁶³ Section 25(4) of the *Mental Capacity Act 2005*.

⁶⁴ Section 25(4) of the *Mental Capacity Act 2005*.

These provisions are also considerably broad in scope. When deciding whether an advance decision applies to the proposed treatment, the Code of Practice for the 2005 Act merely advises healthcare professionals to 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 not 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.⁶⁵

4.44 It has been argued that whilst the broad language of section 25 allows a patient to avail of progress in medical science, it may also allow a court to exploit its provisions, if reluctant to uphold a refusal of treatment.⁶⁶

4.45 Neither the 2005 Act nor the Code of Practice for the 2005 Act clarifies what level of detail is required in order for a refusal of a 'specified' treatment to be applicable. Guidance may be found from the case *W Healthcare NHS Trust v H*.⁶⁷ There, the court accepted that some of the patient's previous statements may have been sufficiently clear, for example, her desire not to be kept alive on "life support machines."⁶⁸ However, the other remaining general statements refusing treatment based on quality of life considerations were insufficiently precise to amount to an applicable advance directive.⁶⁹ Therefore, the court held that she had not refused the artificial nutrition and hydration.

(3) If an advance decision is not valid or applicable

4.46 If an advance decision is not valid or applicable to current circumstances:

- healthcare professionals must consider the advance decision as part of their assessment of the person's best interests if they have reasonable grounds to think it is a true expression of the person's wishes, and
- they must not assume that because an advance decision is either invalid or not applicable, they should always provide the specified

⁶⁵ *Mental Capacity Act 2005 - Code of Practice* at paragraph 9.43.

⁶⁶ Bartlett *Blackstone's Guide to the Mental Capacity Act 2005* (Oxford University Press 2005) at paragraph 2.107.

⁶⁷ [2005] 1 WLR 834.

⁶⁸ *Ibid* at 839 per Brooke LJ.

⁶⁹ *Ibid* at 840 per Brooke LJ.

treatment (including life-sustaining treatment) – they must base this decision on what is in the person’s best interests.⁷⁰

(4) Bias in favour of preserving life

4.47 In determining the validity of an advance care directive, a healthcare professional or a court must engage in a delicate balancing exercise involving the right to self-determination and the principle of the sanctity of life.⁷¹ A number of commentators have concluded that, in cases of doubt, a strong bias in favour of the sanctity of life has emerged.⁷² For example, in England, it has been contended that both the English *Mental Capacity Act 2005*, as well as the common law, apply a bias against the validity or applicability of an advance decision refusing life-sustaining treatment. In *Re T*, Lord Donaldson MR declared that the burden of proof is on those who seek to establish an advance decision that refuses life-sustaining or life-saving treatment. If there is doubt, “that doubt falls to be resolved in favour of the preservation of life.” The evidence must be scrutinised with “especial care”.⁷³ Equally, as can be seen from a comparison of sections 26(2) and 26(3) of the English *Mental Capacity Act 2005*, the criteria for avoiding liability are much stricter than those for disregarding an advance decision.⁷⁴

4.48 By way of contrast, in the Canadian case of *Malette v Shulman*,⁷⁵ there was a considerable degree of doubt on the part of the treating doctor, regarding the validity of an advance refusal of treatment which was contained on a card in the patient’s purse. For example, it was unknown whether the patient might have changed her religious beliefs before the accident, whether the card may have been signed as a result of family or peer pressure, whether

⁷⁰ *Mental Capacity Act 2005 - Code of Practice* at paragraph 9.45.

⁷¹ Denham J acknowledged not only the right to determine one’s own medical treatment, but also that the right to life in Article 40.3 encompasses the concept of the sanctity of life: *In re a Ward of Court (No 2)* [1996] 2 IR 79 at 161.

⁷² Munby “Rhetoric and Reality: The Limitations of Patient Self-Determination in Contemporary English Law” (1998) 14 *Journal of Contemporary Health Law and Policy* 315 at 328-329; Willmott, White and Howard “Refusing Advance Refusals: Advance Directives and Life-Sustaining Medical Treatment” (2006) 30 *Melbourne University Law Review* 211 at 236; Michalowski “Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right” (2005) 68(6) *Modern Law Review* 958.

⁷³ [1992] 4 All ER 649 at 661 per Lord Donaldson MR.

⁷⁴ See paragraphs below on liability under the Mental Capacity Act 2005.

⁷⁵ (1990) 67 DLR (4th) 321 at 331-332 per Robins JA

she had been sufficiently informed of the nature and effect of her decision, whether she still knew the card was in her purse, or whether, if conscious, she might have changed her mind in the face of medical advice. The Ontario Court of Appeal acknowledged the possibility of these events, but concluded that the doctor's doubts as to these matters were "not rationally founded on the evidence before him".⁷⁶ This approach has been embraced by commentators as "robust", and preferable to that taken in England.⁷⁷

(5) Values History

4.49 In deciding whether a directive is applicable to the particular circumstances facing the patient and the doctors, a values history has been propounded as an invaluable aid of interpretation. A values history is a statement of the individual's general values, providing "the information necessary to make a reasonable and thoughtful decision; it does not purport to be the decision itself."⁷⁸ It offers a number of significant benefits. First, it is not limited to specific questions about preferred forms of medical intervention in the event of incompetence. Indeed, the more specific an advance directive is, the more likely it is to vary from the circumstances that actually arise. Second, it "naturally facilitates the recognition and exercise of patient autonomy in the health-care decision-making process."⁷⁹ Third, if a values history is carefully documented in a medical record and updated at regular intervals it can potentially provide the "clearest and most convincing evidence" of the patient's views following a loss of competence.

4.50 In the United States, the "Five Wishes" document, a simple advance directive that is (arguably) legally effective under the laws of 40 different states, is increasing in popularity.⁸⁰ The Five Wishes document "lets your family and doctors know:

1. Which person you want to make health care decisions for you when you can't make them;

⁷⁶ (1990) 67 DLR (4th) 321 at 326- 337 per Robins JA

⁷⁷ Willmott, White and Howard "Refusing Advance Refusals: Advance Directives and Life-Sustaining Medical Treatment" (2006) 30 *Melbourne University Law Review* 211 at 237.

⁷⁸ Furrow et al *Health Law* (vol 2) (1995) at §17-27.

⁷⁹ Rich "The Values History: A New Standard of Care" (1991) 40 *Emory Law Journal* 1109 at 1142-3.

⁸⁰ Developed by Aging with Dignity. The form is available at www.agingwithdignity.org (accessed June 27, 2008).

2. The kind of medical treatment you want or don't want;
3. How comfortable you want to be;
4. How you want people to treat you;
5. What you want your loved ones to know.”

4.51 A values history would be insufficient on its own to guide physicians. As Holmes J stated, “[g]eneral propositions do not decide concrete cases.”⁸¹ Therefore, perhaps the most appropriate approach would be to combine an advance directive with a values history:

“Value-based directives may be easier for patients to complete, because they do not require a knowledge of health problems or medical treatments. However, preference-based directives may be easier for health care professionals to interpret and implement, because they provide more explicit directives regarding treatment. It is difficult to know how to balance these conflicting goals. Since values and preferences represent fundamentally different, but complementary, approaches, instruction directives should contain both these components.”⁸²

This approach would be in line with the suggestion of one English commentator, who has argued that an attempt should be made to interpret the directive by inferring from documentary or extrinsic evidence what the patient’s wishes were.⁸³

(6) Voluntary

4.52 At English common law, an advance care directive must have been given free from undue influence. In *Re T*,⁸⁴ the English Court of Appeal held that a patient who was 34 weeks pregnant and who had refused a blood transfusion, had been subject to the undue of influence of her mother, a Jehovah’s Witness. The court held that physicians had been justified in ignoring the patient’s refusal and administering the transfusion. However, Staughton LJ warned that in order 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.”⁸⁵

⁸¹ *Lochner v New York* (1905) 198 US 43.

⁸² Advance Directives Seminar Group “Advance Directives: Are They an Advance?” *Canadian Medical Association Journal* (1992) 146(2) 129.

⁸³ Michalowski “Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right” (2005) 68(6) *Modern Law Review* 958 at 967.

⁸⁴ [1992] 4 All ER 649.

⁸⁵ [1992] 4 All ER 649 at 669.

4.53 Australian statutes have dealt extensively with the condition that an advance directive must have been made in a voluntary fashion.⁸⁶ In Queensland, the issue of voluntariness is subsumed within the definition of ‘capacity’. An adult does not have capacity unless he or she can “freely and voluntarily” make a decision about a matter.⁸⁷ In the Australian Capital Territory, a directive is void if it is obtained through the use of “violence, threats, intimidation or [if a person] otherwise hinders or interferes with [the maker]...for the purpose of...obtaining” a directive.⁸⁸ Finally, in Victoria, witnesses who sign a refusal of treatment certificate must attest to the fact that they are satisfied that the adult’s “decision is made voluntarily and without inducement or compulsion.”

(7) Interpretation

4.54 One of the greatest problems facing healthcare professionals who must interpret advance care directives is that they are frequently unclear and ambiguous even when they least appear to be. As a result, it has been argued that “signing a living will is imprudent, because at the very least, you risk putting yourself at the mercy of the people who do not know what it means...Philosophical questions aside-why die stupidly?”⁸⁹ The environment in which advance directives are commonly interpreted in will not make the task of interpretation any easier:

“Whereas a complex will can be interpreted at leisure by a probate lawyer trained for the task, a detailed advance directive may fall for more urgent interpretation by a harried and over-worked clinician in a casualty department with no such training in the interpretation of legal documents. Is it prudent to entrust one’s life to what may be a rushed interpretation by a busy hospital doctor?”⁹⁰

4.55 In the absence of legislation on advance directives, the dictum of Denham J in *Re a Ward of Court (No 2)* is instructive when considering the position of advance care directives in an emergency:

⁸⁶ Willmott, White and Howard “Refusing Advance Refusals: Advance Directives and Life-Sustaining Medical Treatment” (2006) 30 *Melbourne University Law Review* 211 at 218.

⁸⁷ Schedule 3 of the *Powers of Attorney Act 1988* (Qld).

⁸⁸ Section 19(1)(b) of the *Medical Treatment Act 1994* (ACT).

⁸⁹ Stone “Advance Directives, Autonomy and Unintended Death” [1994] 8 *Bioethics* 191.

⁹⁰ Power “Bioethics and the End of Life” (2008) 13(1) *Bar Review* 19 at 24.

“Whilst an unconscious patient in an emergency should receive all reasonable treatment pending a determination of their best interests, invasive therapy should not be continued in a casual or ill-considered way.”⁹¹

4.56 In 1994, the UK House of Lords Select Committee on Medical Ethics resolved that “...there should be no expectation that treatment in an emergency should be delayed while enquiry is made about a possible advance directive.”⁹² And, rather interestingly, the Committee referred to the protections traditionally reserved for the bona fide purchaser without notice:

“A doctor who treats a patient in genuine ignorance of the provisions of an advance directive should not be considered culpable if the treatment proves to have been contrary to the wishes therein expressed.”⁹³

4.57 The Code of Practice made under the English *Mental Capacity Act 2005* states that a health care professional must provide treatment in the patient’s best interests, unless they are satisfied that there is an advance decision that is valid and applicable in the circumstances.⁹⁴ However, it also advises that:

“Healthcare professionals should not delay emergency treatment to look for an advance decision if there is no clear indication that one exists. But if it is clear that a person has made an advance decision that is likely to be relevant, healthcare professionals should assess its validity and applicability as soon as possible. Sometimes the urgency of treatment decisions will make this difficult.”⁹⁵

4.58 A rather more complex situation arises when oral statements are issued in emergency care settings. Statutes in British Columbia⁹⁶ and Ontario⁹⁷ require a health care provider to respect advance directives in emergency care

⁹¹ [1996] 2 IR 79 at 158.

⁹² House of Lords Select Committee *Report on Medical Ethics* (London HMSO 1994) HL Paper 21-I at 265.

⁹³ *Ibid.* Cited in Morgan “Odysseus and the Binding Directive: Only a Cautionary Tale?” (1994) 14 *Legal Studies* 411 at 423.

⁹⁴ *Code of Practice – Mental Capacity Act 2005* at paragraph 9.55.

⁹⁵ *Code of Practice – Mental Capacity Act 2005* at paragraph 9.56.

⁹⁶ Section 121 of the *Health Care (Consent) and Care Facility (Admission) Act RSBC 1996*.

⁹⁷ Section 5 of the *Health Care Consent Act SO 1996*.

settings. The health care provider must not provide treatment if there are “reasonable grounds” to believe that a person expressed an “instruction or wish” to refuse specific treatment. It has been argued that the use of the word “wish” indicates that an oral statement may be sufficient.⁹⁸ The only express limitation is that the instruction or wish must be made after the person is 19 years old in British Columbia, or 16 years old in Ontario.

(8) Conclusion

4.59 In the Commission’s view, in order to be valid, the advance care directive must have been created while the author had the capacity to do so. The author of an advance care directive can consent to the treatment which they have refused in the advance care directive, provided they had the capacity to do so. It may not be possible to make the revocation of an advance care directive known. Thus if the patient has done or said anything which puts reasonable doubt in the doctors mind, the doctor should proceed with the treatment. After all, the bias must always be in favour of preserving life. When considering whether the advance care directive is valid under such circumstances, the Commission considers that, the doctor should take into consideration the length of time that has elapsed between the drawing up or revision of the advance care directive and the time it came into effect. However while time may have altered a person’s perspective, it may not necessarily have changed a person’s opinion. A doctor may take into consideration any actions or statements made while the author of the advance care directive was competent.

4.60 In addition, the Commission considers a doctor should make all attempts to decipher what a patient intended in their advance care directive. However, time may make a once clear advance care directive ambiguous. If a doctor is unsure about the advance care directive they should not second guess the wishes of the patient. Bearing these considerations in mind, the Commission turns to set out its provisional recommendations on this:

4.61 *The Commission provisionally recommends that an advance care directive will not be valid if*

- *The author of the advance care directive did not have capacity at the time of its creation*
- *The creation of the advance care directive was not a voluntary act of the author*

⁹⁸ Clough “A Critique of Advance Directives and Advance Directives Legislation” (2006) 11 *Appeal: Review of Current Law and Law Reform* 16 at 26.

- *The author changed their mind and communicated this change of mind*
- *A written advance care directive refusing life-sustaining medical treatment was not witnessed and if the person did not consult with a medical professional*

4.62 *The Commission provisionally recommends that an advance care directive is not applicable if*

- *It is ambiguous in relation to the proposed treatment*
- *If all the circumstances outlined in the advance care directive are 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 author had changed their mind but did not have the opportunity to revoke the advance care directive.*

G Triggering event

4.63 The 1998 King's College Working Party Report raised the vital question of specifying at what point an advance directive should be activated:

"In respect of the triggering event three alternatives are possible. The trigger can be incompetence alone, or incompetence with the addition of a particular condition or disability, or incompetence with the addition of terminal illness. Each of these definitions give rise to particular difficulties. Incompetence alone may cause a living will to be implemented in circumstances which some people would consider inappropriate, for example, a moderate degree of dementia without some other disability. Incompetence plus specified conditions or disabilities may lead to problems because of the impossibility of itemising every conceivable event triggering clinical circumstances, and the uncertainty in interpreting those which are specified. Incompetence plus terminal illness does not capture all the circumstances under which many people would wish a living will to be instituted. It may also cause problems if clinicians interpret terminal illness restrictively, as occurred in the operation of the California *Natural Death Act 1976*."⁹⁹

⁹⁹ Kings' College London *The Living Will: Consent to Treatment at the End of Life* (Working Party Report, Age Concern and Centre of Medical Law and Ethics (1988)).

4.64 In early living will statutes in the United States, it was common to stipulate that advance decisions could only apply when a patient was in a 'terminal condition', or that 'death be imminent.' This limitation was criticised on the basis that "if the intent of living will statutes was to permit the 'natural death' of persons who would otherwise linger for years maintained by modern machinery in a vegetative but 'alive' state," then a requirement that 'death be imminent' regardless of whether treatment is withdrawn or not would defeat the purpose of such statutes.¹⁰⁰

4.65 The Law Commission of England and Wales concluded, however, that such a stipulation would be "wrong and out of place in a scheme which seeks to build and clarify the fundamental legal principle that patients with capacity can refuse *any* treatment."¹⁰¹ Moreover, the phrase 'terminal condition' has no uniformly accepted meaning within the medical profession.¹⁰² The English *Mental Capacity Act 2005* does not contain any such 'terminal conditions', but rather, section 26(1) states that the advance decision will take effect only if the person lacks capacity at the time treatment is to be provided or continued.

4.66 In Victoria, unlike other Australian states, there is a 'current condition' requirement that must be met before a valid statutory advance directive can be completed.¹⁰³ An adult can only complete a directive in relation to a particular condition or conditions from which the adult is suffering at the time of completion.

4.67 The purpose of an advance care directive is to ensure that a person can retain autonomy over any future treatments which may be both foreseen and unforeseen. Thus it would be limiting to require that the maker of an advance care directive be suffering from a terminal illness for it to apply. A person may lose capacity but the treatment described in the advance care directive may never be proposed. Thus the triggering event for activating an advance care directive would not be the loss of capacity alone.

¹⁰⁰ Gelfand "Living Will Statutes: The First Decade" (1987) *Wisconsin Law Review* 737 at 742.

¹⁰¹ Law Commission for England and Wales *Consultation Paper on Mentally Incapacitated Adults and Decision-Making: An Overview* (No 119 1991) at paragraph 6.9.

¹⁰² Rich "The Values History: A New Standard of Care" (1991) 40 *Emory Law Journal* 1109 at 1114.

¹⁰³ Section 5(1) of the *Medical Treatment Act 1988* (Vic). See Willmott, White and Howard "Refusing Advance Refusals: Advance Directives and Life-Sustaining Medical Treatment" (2006) *Melbourne University Law Review* 7.

4.68 *The Commission provisionally recommends that before an advance care directive is activated, the author of the advance care directive must lack capacity and the treatment proposed must be the treatment outlined in the advance care directive.*

H Revocation

(1) Informal approach

4.69 The English *Mental Capacity Act 2005* allows informal revocations and alterations. Section 24(3) of the 2005 Act enables the maker of an advance decision to withdraw or alter an advance decision at any time when he has capacity to do so.¹⁰⁴ Importantly, the 2005 Act states that a withdrawal (including a partial withdrawal) or an alteration need not be in writing.¹⁰⁵ Therefore, the maker of an advance decision may simply withdraw or alter their decision verbally. The Code of Practice for the 2005 Act notes that this can be done at any time, even if the maker is on “the way to the operating theatre or immediately before being given an anaesthetic.”¹⁰⁶ However, it does recommend that healthcare professionals should record a verbal cancellation or alteration in healthcare records, which then forms a written record.¹⁰⁷

4.70 The importance of adopting a flexible approach to revocation was highlighted by Munby J in *HE v A Hospital NHS Trust*.¹⁰⁸

“...it is fundamental that an advance directive is, of its very essence and nature, inherently revocable. An irrevocable advance directive is a contradiction in terms and is, in my judgment, a legal impossibility. An advance directive is, after all, nothing more or less than the embodiment of the patient's autonomy and right of self-determination. A free man can no more sign away his life by executing an irrevocable advance directive refusing life-saving treatment than he can sign away his liberty by subjecting himself to slavery. Any

¹⁰⁴ Section 24(3) of the *Mental Capacity Act 2005*.

¹⁰⁵ Section 24(4) and (5) of the *Mental Capacity Act 2005* (unless the decision relates to the refusal of life-sustaining treatment, in which case section 25(5) applies).

¹⁰⁶ *Mental Capacity Act 2005 - Code of Practice* at paragraph 9.31.

¹⁰⁷ *Ibid.*

¹⁰⁸ Discussed in paragraph 4.41 above.

condition in an advance directive purporting to make it irrevocable is contrary to public policy and void.”¹⁰⁹

(2) Incapacity and revocation

4.71 A difficult question arises when a patient attempts revocation when incompetent. In other words, can the incompetent patient change his or her mind?

4.72 In principle, the onset of incapacity should be a triggering event that makes the advance care directive irrevocable. Cantor argues that to hold otherwise would give “dominion to the deranged expressions of [seriously demented] persons” and “would make a mockery of self-determination when the expressions override a carefully considered advance directive.”¹¹⁰ To implement the advance directive without the patient’s co-operation would however, not only infringe whatever remnants of autonomy that the patient retains, but would also be of concern to a caring and beneficent profession.¹¹¹ Moreover, Kadish propounds that continuing treatment is justified on the sole basis that it shows “compassion for the human being before us.”¹¹² In response, Olick warns that appealing to “human compassion alone as an ethical norm smuggles a current experiential best interests standard in the back door” and is “susceptible to ready abuse.”¹¹³ He proposes a non-categorical approach that an advance care directive “should be treated *as if suspended* as long as the patient continues to manifest a desire for continued life.”¹¹⁴

4.73 Munby J raised, this question in *HE v A Hospital NHS Trust*. He observed that the patient was essentially in the “twilight position” of having made an advance decision refusing treatment while competent, but appeared compliant with treatment following a loss of capacity.¹¹⁵ The English *Mental*

¹⁰⁹ EWHC 1017; [2003] 2 FLR 408 at paragraph 37.

¹¹⁰ Cantor *Advance Directives and the Pursuit of Death with Dignity* (Bloomington: Indiana University Press 1993) at 85.

¹¹¹ McLean “Advance Directives and the Rocky Waters of Anticipatory Decision-Making” (2008) 16(1) *Medical Law Review* 1 at 19.

¹¹² Kadish “Letting Patients Die: Legal and Moral Reflections” (1992) 80 *California Law Review* 857 at 876.

¹¹³ Olick *Taking Advance Directives Seriously: Prospective Autonomy and Decisions Near the End of Life* (Georgetown University Press Washington DC 2001) at 192.

¹¹⁴ *Ibid* at 193.

¹¹⁵ Olick *Taking Advance Directives Seriously: Prospective Autonomy and Decisions Near the End of Life* (Georgetown University Press Washington DC 2001) at fn 2.

Capacity Act 2005 does little to clarify the situation. On the basis of section 24(3) of the 2005 Act, the passive compliance of a patient would not be enough to revoke an advance decision as it refers specifically to capacity:

“P may withdraw or alter an advance decision at any time when he has the capacity to do so.”

Section 25(2)(c) could be interpreted to include decisions made when a patient has lost capacity as there is no explicit reference to capacity. It states that an advance decision will be invalid if:

“P has done anything else clearly inconsistent with the advance decision remaining his fixed decision.”

It may also be argued that section 25(2)(c) should be interpreted in light of section 24(3). However, had the UK Parliament wanted section 25(2)(c) to be limited to adults with capacity, then it could have made this explicit in the section as they did in section 24(3).¹¹⁶

4.74 More controversial issues arise if the treatment requested is life-sustaining, as such treatment raises questions regarding the right to life in Article 40.3 of the Constitution of Ireland and Article 2 of the European Court of Human Rights (ECHR). The right to life under Article 40.3 is enjoyed by everyone, including those lacking capacity.¹¹⁷ There is no Irish or ECHR jurisprudence that addresses how a competent, advance refusal of a life-sustaining treatment should affect the current and incompetent views of an individual apparently now wishing to have that treatment.

4.75 In *Re Martin*¹¹⁸ demonstrates the danger of disregarding an advance directive based on the incompetent patient's wishes. In that case, the patient suffered a traumatic brain injury and as a result was unable to walk and talk.

¹¹⁶ Olick *Taking Advance Directives Seriously: Prospective Autonomy and Decisions Near the End of Life* (Georgetown University Press Washington DC 2001) at 20. Bartlett *Blackstone's Guide to the Mental Capacity Act 2005* (Oxford University Press 2005) at paragraph 2.115.

¹¹⁷ *In re a Ward of Court (No 2)* [1996] 2 IR 79 at 169 per Denham J: “Respect is given to the life of the ward. Her life is no less protected or guarded than any other person's. Her rights as a citizen stand.”

¹¹⁸ 538 NW2d (Mich 1995) 229 cited in Michalowski “Advance Refusal of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right” (2005) 68(6) *Modern Law Review* 958 at 980.

(3) Intention to revoke

4.76 A number of Australian statutes have addressed the rather difficult situation in which an adult may have changed his mind, but has failed to actually revoke the directive. In the Northern Territory¹¹⁹ and South Australia,¹²⁰ a health professional must not comply with an advance directive if he believes that the adult intended to revoke that directive. Similarly, in the Australian Capital Territory,¹²¹ a health professional must not comply with an advance directive if he believes on reasonable grounds that the adult has changed his mind since making the directive.

(4) Conclusion

4.77 While a patient has the right to refuse medical treatment, a patient can also change their mind and consent to the treatment. The same applies for an advance care directive. While a person has the capacity, they may revoke their advance care directive. Certain formalities are required before a refusal of life-sustaining treatment is valid. The Commission recommends that such formalities are not necessary to revoke an advance care directive which refuses life-sustaining medical treatment. Where a person revokes a refusal to life-sustaining treatment, in the Commission's view, they are exercising their right to life. The preference must always be in favour of preserving life and a person must not be inhibited in the exercise of their right to life by virtue of failing to comply with certain formalities. Thus the Commission has concluded that the revocation of an advance care directive can be written or formal regardless of the form in which it was created, but it recognises that this is a complex matter and invites submissions on this part.

4.78 *The Commission provisionally recommends that a competent person can verbally revoke their advance care directive regardless of whether there is a verbal or written advance care directive and also welcomes submissions on this point.*

I Review

4.79 Should advance care directives be subject to regular review? As Lord Goff noted in *Airedale NHS Trust v Bland*,¹²² special care may be necessary to ensure that a prior refusal of consent is still properly to be regarded as

¹¹⁹ Section 4(3)(a) of the *Natural Death Act 1988* (NT).

¹²⁰ Section 7(3)(b) of the *Consent to Medical Treatment and Palliative Care Act 1995* (SA).

¹²¹ Section 12(b) of the *Medical Treatment Act 1994* (ACT).

¹²² [1993] 1 All ER 821 at 866.

applicable in the circumstances which have subsequently occurred. US studies have measured the stability of advance care directive preferences over periods of up to two years. One such study examined the treatment preferences of 51 older people two years after they completed their directives. Most treatment preferences remained moderately stable. However, investigators also found that when the preferences of some participants had changed, they were often unaware of it. Therefore, they were unlikely to alter their directives, and were left with directives that did not accurately state their treatment preferences.¹²³

4.80 The English *Mental Capacity Act 2005* does not require individuals to review an advance decision. However, the Code of Practice for the 2005 Act suggests that “[a]nyone who has made an advance decision is advised to regularly review and update it as necessary.”¹²⁴ The Scottish Executive’s *Guide to Advance Statements* states that an individual does not have to review an advance statement, but that it is a “good idea” to do so every six months.¹²⁵ The Irish Council for Bioethics recommended that individuals review and update their advance care directive on a relatively regular basis to reflect changes in medical science and also any changes in the individual’s values and beliefs.¹²⁶

(1) Time limits

4.81 Should an advance care directive lapse after a specified number of years unless reviewed? On the one hand, it “might be undesirable if the person’s fate should be determined by means of an instrument executed decades ago and now forgotten”.¹²⁷ This was one of the reasons which led the British Medical Association to reject the idea of legally enforceable advance directives outright.¹²⁸ On the other hand, there is a great likelihood of people forgetting to renew their advance directive and if documents had to be re-executed periodically to ensure their ongoing validity, it would “create an

¹²³ Dresser “Precommitment: A Misguided Strategy for Securing Death With Dignity” (2003) 81 *Texas Law Review* 1823 at 1835.

¹²⁴ *Mental Capacity Act 2005 - Code of Practice* at paragraph 9.29.

¹²⁵ *The New Mental Health Act: A Guide to Advance Statements* (Scottish Executive 2005) at 11.

¹²⁶ *Is it Time for Advance Healthcare Directives?* (The Irish Council for Bioethics 2007) at 35.

¹²⁷ Kings’ College London *The Living Will: Consent to Treatment at the End of Life* (Working Party Report, Age Concern and Centre of Medical Law and Ethics (1988) at 59.

¹²⁸ British Medical Association “Advance Declarations” in *Euthanasia* (London BMA 1988) chapter 12 at paragraph 234.

unjustifiable gravy train for lawyers.”¹²⁹ It was on this basis that the working party set up in England in 1988 by Age Concern recommended that the provisions of an advance directive should be reviewed on a regular basis every five to ten years, but concluded that no obligatory review or time limit should be imposed.¹³⁰

4.82 In a similar vein, the Code of Practice for the English 2005 Act specifies that if decisions are made a long time in advance, they are not automatically valid or applicable.¹³¹ However, it does warn that such decisions “may raise doubts” and healthcare professionals should take “special care”.¹³²

4.83 Changes in medical science can bring about changes in a person’s attitudes expressed in an advance care directive. For various reasons, however, a person may not amend their advance care directive. Thus people must be encouraged to review their advance care directive regularly. However, a change in medical science or a lapse of time will not of course necessarily change a persons mind about their future treatment plans. To assume so would place an unnecessary burden and possibly unnecessary expense on authors of advance care directives. The Commission recommends that while advance care directives should be reviewed regularly, this should not be a statutory requirement. The Commission recommends, however, that any set of guidelines to complement the legislation should state that a medical practitioner can take into consideration the length of time which has elapsed between the making or reviewing of the advance care directive and the activation of the advance care directive.

4.84 *The Commission provisionally recommends that, while advance care directives should be reviewed regularly, there should be no time limit put on their validity.*

J Storing an advance care directive

4.85 Perhaps the most practical issue regarding the implementation of advance care directives is how to guarantee that they will get to the appropriate physician at the appropriate time. As Fagerlin and Schneider have wryly noted,

¹²⁹ Bartlett *Blackstone’s Guide to the Mental Capacity Act 2005* (Oxford University Press 2005) at paragraph 2.107.

¹³⁰ Kings’ College London *The Living Will: Consent to Treatment at the End of Life* (Working Party Report, Age Concern and Centre of Medical Law and Ethics (1988) at page 59.

¹³¹ *Mental Capacity Act 2005 - Code of Practice* at paragraph 9.29.

¹³² *Ibid* at paragraphs 9.29 and 9.51.

“long can be the road from the drafter’s chair to the ICU bed.”¹³³ This can be for a number of reasons.¹³⁴ First, advance care directives may be made years in advance of any health care treatment. Second, the existence, let alone location of an instructional directive may be unknown to the attending physicians and family members. Third, if admitted to hospital in an emergency situation, a patient may be too overwhelmed by the circumstances to mention or even remember their advance care directive. One US study found that only 26% of patients who had previously executed advance care directives had their directives accurately recorded in their hospital charts.¹³⁵ In another US study, only 35% of nursing home patients who were transferred to hospital had their advance directives with them.¹³⁶ It has been argued that this is a reason why proxy-type directives usually work better since it is likely that a copy will have been given to the proxy.¹³⁷

4.86 The English *Mental Capacity Act 2005* does not refer to any particular method of storing advance decisions. The Code of Practice for the 2005 Act notes that it is the responsibility of the maker of the advance decision to ensure that their decision will be drawn to the attention of healthcare professionals when it is needed.¹³⁸ It suggests that makers should inform family and friends as to the existence of an advance decision, or that makers should carry a card or wear a bracelet.¹³⁹ Kutner proposed that the maker of a living would carry the document “on his person at all times, while his wife, his personal physician, a lawyer or confidant would have the original copy.”¹⁴⁰

¹³³ Fagerlin and Schneider “Enough: the Failure of the Living Will” (2004) 34(2) *Hastings Centre Report* 30 at 35.

¹³⁴ Clough “A Critique of Advance Directives and Advance Directives Legislation” (2006) 11 *Appeal: Review of Current Law and Law Reform* 16 at 31.

¹³⁵ Morrison et al “The Inaccessibility of Advance Directives on Transfer from Ambulatory to Acute Care Settings” (1995) 274(6) *JAMA* 478.

¹³⁶ Danis et al “A Prospective Study of the Impact of Patient Preferences on Life-Sustaining Treatment and Hospital Cost” (1996) 24(11) *Critical Care Medicine* 1811-17.

¹³⁷ Capron “Advance Directives” in Kuhse & Sieger (ed) *A Companion to Bioethics* (Blackwell Publishing 1998) at 270.

¹³⁸ *Mental Capacity Act 2005 - Code of Practice* at paragraph 9.38.

¹³⁹ *Ibid* at paragraph 9.38.

¹⁴⁰ Kutner “Due Process of Euthanasia: The Living Will, A Proposal” (1969) 44 *Indiana Law Journal* 539 at 551.

4.87 There are some registries for the storage of advance care directives. The US Living Will Registry stores the advance care directives of any individual who has registered through a member healthcare provider.¹⁴¹ Denmark's Ministry of Health has set up a national Living Will Data Bank (Livstestamenteregistret). Notably, if a physician is considering initiating life-prolonging treatment of an irreversibly dying patient, he is obligated to check with the Living Will Data Bank whether or not the patient has filed a living will.¹⁴² In Singapore, a register of advance medical directives has been established by statute, and a person who makes an advance medical directive must register it with the Registrar.¹⁴³ A health provider is prohibited from acting on an unregistered directive.¹⁴⁴ The Commission sees the obvious benefit of a Register but also recognises that this creates the potential for complexity and costs, which may not be justified. For this reason, the Commission invites submissions on this matter.

4.88 *The Commission invites submissions on whether it is necessary to have a central filing system for advance care directives.*

¹⁴¹ See www.uslivingwillregistry.com.

¹⁴² Section 4 of §26 of the *Health Act 2005*. The registration procedure currently costs about €7. See Nys et al "Patients Rights in the EU: Denmark" European Ethical – Legal Papers N° 2 (2007). Available at [www. http://www.orpha.net/actor/EuropaNews/2007/doc/denmarkbk.pdf](http://www.orpha.net/actor/EuropaNews/2007/doc/denmarkbk.pdf).

¹⁴³ Section 5(1) of the *Advance Medical Directive Act 1996* (Singapore).

¹⁴⁴ Section 5(3) of the *Advance Medical Directive Act 1996* (Singapore).

CHAPTER 5 FRAMEWORK FOR COMPLIANCE WITH ADVANCE CARE DIRECTIVES

A Introduction

5.01 In this Chapter the Commission discusses the legal consequences for health care professionals of not complying with the terms of an advance care directive that meets the criteria set out by the Commission in the previous Chapters of this Consultation Paper. In Part B, the Commission sets out the current law, particularly in terms of medical treatment given without consent (and where the doctrine of medical necessity does not apply). In summary, the current law provides for a range of potential criminal and civil liability as well as possible scope for professional disciplinary action. The current law also provides a series of defences to such issues of liability, notably, that the medical professional acted on an advance care directive, but the Commission considers that a statutory framework should underpin current practice and deal with difficult gaps. In Part C, the Commission sets out the scope of a statutory scheme which would deal with the potential range of liability. In this respect, the Commission refers to the existing statutory framework for clinical trials by way of a statutory analogue for a proposed scheme.

B Current Irish law

(1) *Criminal law*

(a) *Following a lawful advance care directive: homicide*

5.02 If a doctor follows a lawful advance care directive that refuses life-sustaining treatment, he or she is not guilty of gross negligence manslaughter. Gross negligence manslaughter involves a high risk that substantial personal injury will follow the accused's negligent act or omission. The accused must intend to do the act that causes death or, where there is a special duty to act, an omission to do something which would prevent death from occurring.¹ As Lord Mustill observed in the English case of *Airedale NHS Trust v Bland*:²

¹ Law Reform Commission *Report on Homicide: Murder and Involuntary Manslaughter* (LRC 87-2008) at paragraphs 4.30-4.59 and paragraph 6.12.

² [1993] 1 All ER 821.

“If an act resulting in death is done without lawful excuse and intent to kill it is murder. But an omission to act with the same result and the same intent is in general no offence at all.”³

The main common law exception to this is that a person may be criminally liable for an omission if there is a relationship with the victim that places him or her under a duty to act.⁴ In 1986, Costello J, writing extra-judicially, first discussed whether a physician who turns off life-support measures would be guilty of homicide under Irish law. He concluded that although switching off the system would be a positive act, such an act would not result in harm. Rather, the cause of death would be the failure to switch on the system again, “a failure which can properly be regarded as an omission.”⁵

5.03 In 1993, the UK House of Lords held in the *Bland* case, that it was lawful to discontinue the nasogastric tube feeding of a patient who was in a persistent vegetative state on the basis that the withdrawal of such treatment was properly classified as an omission. Lord Goff observed and agreed with the suggestion of Professor Glanville Williams that when a doctor switches off a life-support machine, his conduct “is in substance not an act but an omission to struggle’ and that ‘the omission is not a breach of duty by the doctor, because he is not obliged to continue in a hopeless case’.”⁶

5.04 In Ireland McAuley and McCutcheon observe that the Supreme Court provided a cursory analysis of the act/omission distinction in *In re a Ward of Court (No 2)*.⁷ Hamilton CJ cited Bingham MR in *Bland* where he highlighted

³ [1993] 1 All ER 821 at 890 per Lord Mustill.

⁴ *R v Stone and Dobinson* [1977] QB 358.

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

⁶ *Airedale NHS Trust v Bland* [1993] 1 All ER 821 at 867, Lord Goff citing Williams *Textbook of Criminal Law* (2nd ed 1983) at 282. He continued at 867-868: “It is true that it may be difficult to describe what the doctor actually does as an omission, for example where he takes some positive steps to bring the life support to an end. But discontinuance of life support is, for present purposes, no different from initiating life support in the first place. In each case, the doctor is simply allowing his patient to die in the sense that he is desisting from taking a step which might, in certain circumstances, prevent his patient from dying as a result of his pre-existing condition; and as a matter of general principle an omission such as this will not be unlawful unless it constitutes a breach of duty to the patient.”

⁷ McAuley and McCutcheon *Criminal Liability* (Round Hall Sweet & Maxwell 2000) at 183 fn 27.

that the case “is not about euthanasia, if by that is meant the taking of positive action to cause death”⁸ whilst O’Flaherty J considered that the case was not about euthanasia, as “euthanasia in the strict and proper sense relates to the termination of life by a *positive* act,”⁹ but rather letting nature take its course. It is interesting to note the dissent of Egan J who argued that the removal of treatment would be the cause of death:

“It matters not how euphemistically it is worded. The inevitable result of removal would be to kill a human being.”¹⁰

Feenan concurs with the conclusion of Egan J, arguing that it is irrelevant whether the withdrawal of feeding is treated as an act or omission as it does not affect the basic *actus reus* of homicide – to cause death. Instead, he argues that the Supreme Court could have clarified any remaining doubt by holding that:

“the killing was not, pursuant to section 4(1) of the *Criminal Justice Act 1964*, an unlawful killing in so far as the doctor was not legally required – in the view of the ward’s prolonged and irreversibly vegetative condition, the intrusiveness and probable painfulness of treatment, and her rights to a natural death, privacy and bodily integrity – to provide treatment which had no curative effect and was intended merely to prolong life.”¹¹

5.05 However, it is important to stress, as indeed Lord Goff did in *Bland*, that the law draws a “crucial distinction” between cases in which a doctor withdraws life-sustaining treatment as discussed above, and those in which a doctor actively administers a legal drug to bring a patient’s life to an end.¹² The latter activity constitutes euthanasia and is illegal.

(b) Disregarding a lawful advance care directive: assault

5.06 Medical treatments are assaults, to which consent provides a defence. Section 2(1) of the *Non-Fatal Offences Against the Person Act 1997* provides that:

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

⁸ [1996] 2 IR 79 at 120.

⁹ *Ibid* at 130 (emphasis added).

¹⁰ *Ibid* at 136.

¹¹ Feenan “Death, Dying and the Law” (1996) 14 ILT 90 at 93.

¹² *Airedale NHS Trust v Bland* [1993] 1 All ER 821 at 867 Lord Goff.

- (a) directly or indirectly applies 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 the consent of the other.”

5.07 Madden has considered the possibility that a doctor could be prosecuted for assault for inflicting treatment on the patient without consent if he disregards an advance directive. However, she concludes that as 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

(i) Defence of necessity

5.08 The defence of necessity may be used to relieve a healthcare professional of criminal liability where he or she does not follow the patient’s wishes as previously expressed in an advance care directive.¹⁴ However, the circumstances surrounding the medical intervention will be crucial when considering the availability of such a defence.¹⁵ In *Re a Ward of Court (No 2)*,¹⁶ Denham J acknowledged that one of the rare exceptions to the requirement of consent to medical treatment by adults with capacity is in a medical emergency where the patient is unable to communicate.¹⁷

5.09 Lord Goff in *Re F (Mental Patient: Sterilisation)*¹⁸ felt that the doctrine applied to more than emergency situations. He felt that “[t]he principle is one of necessity, not of emergency” and could extend to routine treatment of persons

¹³ Madden *Medicine Ethics & the Law* (Tottel Publishing 2002) at 510 fn 75.

¹⁴ See Charleton, McDermott and Bolger *Criminal Law* (Butterworths 1999) at paragraph 15.29. The Commission has previously observed that the law is not settled in Ireland in relation to the ambit of the doctrine of necessity, in particular, the circumstances which will create the requisite ‘necessity to act’, and what such necessity to act entails: see Law Reform *Commission Consultation Paper on Vulnerable Adults and the Law: Capacity* (LRC CP 37-2005) at paragraphs 7.38-7.51.

¹⁵ Charleton, McDermott and Bolger *Criminal Law* (Butterworths 1999) at paragraph 15.27.

¹⁶ [1996] 2 IR 79.

¹⁷ *Ibid* at 156.

¹⁸ [1989] 2 All ER 545.

lacking capacity.¹⁹ As the Commission pointed out in its *Consultation Paper on Vulnerable Adults and the Law*,²⁰ the Irish courts have not had the opportunity to set clear boundaries to the scope of the doctrine of necessity and its application to medical treatment of adults who lack capacity to consent but have not been made a Ward of Court.²¹ The Commission submitted that the lack of clarity on the doctrine in Irish law has led to conflicting reactions. Some medical professionals may err on the side of caution and carry out medical treatment on a patient lacking capacity in a life and death situation only. Other medical professionals may rely on the doctrine of necessity for all medical treatment of an adult who lacks the capacity to consent.

5.10 Although a patient may have made an advance care directive, if it has not been communicated to the healthcare professional, it would appear that a doctor is justified in treating the patient on the basis that there is a public interest in preserving the patient's life. A doctor will therefore not be liable for assault. Conversely, if a doctor is aware that an advance care directive exists which clearly communicates the patient's wishes, he or she will be unable to rely upon the defence of necessity.

(2) Concealment or Destruction of an Advance Care Directive

5.11 There is no general offence for destroying a legal document. Section 11 of the *Criminal Justice (Theft and Fraud Offences) Act 2001* states:

“a person is guilty of an offence if he or she dishonestly, with the intention of making a gain for himself or herself or another, or of causing loss to another, destroys, defaces or conceals any valuable security, any will or any testamentary document or any original document of or belonging to, or filed in, any court or any government department or office.”

As can be seen, section 11 of the 2001 Act could not apply to the destruction or concealment of an advance care directive as there is unlikely to be any “gain” for the person involved.

5.12 Similarly section 20(1) of the English *Theft Act 1968* states that the destruction of valuable securities, wills and government documents, for the purpose of gain, is an offence. The Law Commission for England and Wales considered that the destruction or concealment of an advance care directive is

¹⁹ [1989] 2 All ER 545 at 565.

²⁰ Law Reform Commission *Consultation Paper on Vulnerable Adults and the Law: Capacity* (LRC CP 37-2005).

²¹ *Ibid* at paragraph 7.43.

not covered under this act.²² The Law Commission thus recommended the creation of a new offence. But the English *Mental Capacity Act 2005* which was largely influenced by the Law Commissions recommendations does not include such an offence.

5.13 If an advance care directive is concealed or destroyed by a member of the medical profession, it could constitute professional misconduct. Currently, however, no liability would attach to a person, other than a medical professional, who concealed or destroyed an advance care directive.

(3) Civil law

(a) Contract

5.14 The doctor-patient relationship is governed in part by principles of contract law. Actions in contract are thought to be more advantageous to patients than those in negligence, as they give rise to more onerous obligations upon the doctor. Moreover, they are actionable without the need to prove negligence. Nonetheless, claims are rarely taken in contract as tort actions tend to attract higher damages.²³

(b) Tort

(i) Professional negligence

5.15 The key elements of the tort of negligence are: first, that the doctor owed the patient a duty of care; second, that the doctor breached that duty, which will occur if “he has been proved to be guilty of such failure as no medical practitioner of equal specialist or general status and skill would be guilty of if acting with ordinary care”;²⁴ and finally, that the breach of duty caused harm to the patient. Harm in wrongful living actions, as discussed below, is centred on the prolongation of life whereas harm in both negligence and battery actions is that caused by the administration of undesired medical treatment. However, it would appear that courts in the United States have decided that any injury

²² Law Commission of England and Wales *Report on Mental Capacity* (No 231 1995) at paragraph 5.38.

²³ See Kennedy and Grubb *Medical Law* (3rd ed Butterworths 2000) at 272-277; Mills *Clinical Practice and the Law* (2nd ed Tottel Publishing 2007) at paragraphs 3.42-3.61; Tomkin and Hanafin *Irish Medical Law* (Round Hall Press Dublin 1995) at 64-66.

²⁴ *Dunne v National Maternity Hospital* [1989] IR 91 AT 108-110.

associated with unwanted lifesaving medical treatment is inextricably bound to the injury of prolonging life, and is therefore not a recognisable harm.²⁵

(I) *Breach of duty*

5.16 Although in theory the civil claim for professional negligence is available to plaintiffs whose advance care directives have been disregarded, it would appear that the reality is quite different. Demonstrating that a doctor owes a patient a duty of care is generally unproblematic. However, the patient must then prove that the doctor breached that duty. In the US decision *Allore v Flower Hospital*,²⁶ the plaintiff's husband had been resuscitated by the defendant hospital, even though he had previously asked not to be resuscitated in his living will. In Ohio, the relevant standard of care is "that of a reasonable specialist practising medicine...in the light of present day scientific knowledge in that speciality field."²⁷ In the *Allore* case, it was held that resuscitating the plaintiff's husband did not constitute a breach of this standard. In *Cruzan v Director Missouri Department of Health*,²⁸ the United States Supreme Court had recognised a constitutionally protected liberty interest under the due process clause in a person's refusal of life-sustaining medical treatment. However, it would appear from the *Allore* case that the focus had shifted "away from the patient's right to refuse medical treatment to determining the acceptable standard within the medical community."²⁹

(II) *Drawing the line of causation between infringement of the right to refuse treatment and damages resulting from undesired treatment*³⁰

5.17 A patient must also prove that the breach of duty caused harm. Another US case of *Anderson v St Francis-St George Hospital*³¹ demonstrates

²⁵ Donohue "'Wrongful Living': Recovery for a Physician's Infringement on an Individual's Right to Die" (1997-1998) 14 *Journal of Contemporary Health Law and Policy* 391 at 394.

²⁶ (1997) 699 NE 2d 560.

²⁷ *Bruni v Tatsumi* (1997) 346 NE 2d 673.

²⁸ (1990) 497 US 261 as discussed in paragraph 2.24, above.

²⁹ Tyminski "The Current State of Advance Directive Law in Ohio: More Protective of Provider Liability than Patient Rights" (2004-2005) 19 *Journal of Law and Health* 411 at 431.

³⁰ Donohue "'Wrongful Living': Recovery for a Physician's Infringement on an Individual's Right to Die" (1997-1998) 14 *Journal of Contemporary Health Law and Policy* 391 at 403.

³¹ (1996) 671 NE 225.

the enormous difficulty plaintiffs may face when recovering damages for infringement of their right to refuse life-sustaining treatment, whether they bring a civil claim based upon the traditional torts of negligence, battery³² or the tort of wrongful living³³ - namely, the courts' reluctance to recognise life as a compensable harm entitling the plaintiff to damages. In *Anderson*, the defendant hospital violated an 82 year old patient's Do Not Resuscitate (DNR) order. The patient, Mr Winter, when admitted to hospital for chest pain, informed his doctor that, if his heart failed, he did not wish to be resuscitated. The doctor entered a DNR order on his chart. Three days later he suffered a heart attack. A nurse, who was unaware of the DNR order, resuscitated him with defibrillation. Two days later, he suffered a stroke which left his right side paralysed until his death two years later. His estate brought a civil claim against the hospital based on two grounds. The first claim sought damages for medical treatment to which Mr Winter did not consent under the traditional torts of negligence and battery. The second claim was that Mr Winter had suffered a wrongful living, as a result of the unwanted treatment.

5.18 In relation to the negligence and battery claims, the Ohio Court of Appeals held that "[i]f an injury occurs in a natural, continuous and unbroken sequence", it is reasonably foreseeable, and the tortfeasor is responsible for it. The court stated that the plaintiff could therefore recover all damages related to the infringement on the right to refuse life-sustaining treatment. Such damages included medical expenses, extraordinary expenses related to pain, care, suffering and emotional distress.

5.19 The Supreme Court of Ohio overturned the holding and dismissed the claim on the basis that neither causation nor damage had been established. First, although the patient was defibrillated, there was no evidence that the defibrillation itself caused the patient's stroke or subsequent suffering in any way other than simply prolonging his ailing life. The court reasoned that when an ailing, 82 year old man's life is prolonged, subsequent difficulties could foreseeably follow resuscitation without having been caused by the defibrillation. The only harm caused by the defibrillation was the prolonging of Mr Winter's life. To award compensation for such harm was unacceptable to the court: "[t]here are some mistakes, indeed even breaches of duty...that people make in this life that affect the lives of others for which there simply should be no monetary compensation."³⁴ The Court's approach to causation prevented the patient's estate from claiming general damages for pain and suffering associated with the stroke. Instead, potential damages were limited to those

³² See paragraph 5.20.

³³ See paragraph 5.26.

³⁴ (1996) 671 NE 225 at 228.

suffered directly from the negligent conduct or battery resulting from refused medical treatment. These damages were limited to nominal damages because the defibrillation in itself was physically harmless.³⁵

(ii) Battery

5.20 Does a healthcare professional commit a battery if he or she carries out medical treatment despite the existence of an advance care directive? A battery is the direct application of physical contact on the person of another without his or her consent, express or implied.³⁶ It is not an essential ingredient in the tort that there is a hostile intention, but the contact must have directly resulted from the defendant's act.³⁷

5.21 In their discussion of battery, McMahon and Binchy cite *Re a Ward of Court (No 2)*³⁸ in maintaining that an autonomous person has the legal right to refuse physical contact "however benevolent the motives of the other party and however necessary that contact may be for the health or even life of the person who refuses it."³⁹ In *Re a Ward of Court (No 2)*,⁴⁰ Denham J argued that if a patient does not consent to medical treatment it may be a battery in criminal law.⁴¹

5.22 If Irish courts choose to adopt the approach of the Court of Appeals of Ohio in *Estate of Leech v Shapiro*,⁴² there may well be a basis for a civil claim in tort for the infringement of the right to refuse such contact. There, a patient who had been maintained on life support against her express wishes recovered all extraordinary and unnecessary medical expenses resulting from the non-consensual treatment, as well as for her pain and suffering. The Court held that

³⁵ Donohue "Wrongful Living': Recovery for a Physician's Infringement on an Individual's Right to Die" (1997-1998) 14 *Journal of Contemporary Health Law and Policy* 391 at 410-411.

³⁶ See Mc Mahon and Binchy *Law of Torts* (3rd ed Butterworths 2000) at paragraphs 22.11 – 22.19. Battery has been described colloquially as "assault" in a number of judgments. For example, see *Walsh v Family Planning Services* [1992] 1 IR 496 per O'Flaherty J.

³⁷ *Leame v Bray* (1803) 3 East 593 at 603.

³⁸ [1996] IR 79.

³⁹ McMahon and Binchy *Law of Torts* (3rd ed Butterworths 2000) at paragraph 22.13.

⁴⁰ [1996] 2 IR 79.

⁴¹ *Ibid* at 156.

⁴² (1984) 469, 1052 NE2d.

“[a] physician who treats a patient without consent commits a battery, even though the procedure is harmless or beneficial”.⁴³ If Irish courts, however, adopt the same limited approach to causation and harm as the Supreme Court of Ohio in the *Anderson* case, it is unlikely that a plaintiff will succeed in an action in tort (although it should be noted that the Supreme Court of Ohio did suggest that health care providers would be liable in battery for any damages “directly” caused by unwanted treatment, such as tissue burns or broken bones).⁴⁴

5.23 It appears that the English courts are also reluctant to find physicians liable in the tort of battery. In *Re B*⁴⁵ a 43-year old tetraplegic patient had repeatedly requested the removal of ventilation for a number of months. Although she was competent, her physicians felt unable to comply with her request, suggesting instead that she consider a one-way weaning process, whereby support would be gradually reduced. Butler-Sloss P held that this was a solution “designed to help the treating clinicians and the other carers and not in any way designed to help Ms B.”⁴⁶ Nevertheless, although the physicians had knowingly committed an ongoing battery, Butler-Sloss P declined to impose liability, holding that Ms B had been cared for:

“to the highest standards of medical competence and with devotion...Ironically this excellent care has to some extent contributed to the difficulties for the Hospital. Ms B has been treated throughout in the ICU in which the medical and nursing team are dedicated to saving and preserving life, sometimes in adverse medical situations. As Dr C said, they are trained to save life.”⁴⁷

It has been argued that this judicial hesitance to find physicians liable in clear-cut cases may serve to foster an attitude of non-compliance with advance care directives on the part of the medical profession.⁴⁸

5.24 In contrast, the Canadian courts appear to take a more stringent view. In *Malette v Shulman*,⁴⁹ the patient was seriously injured in a car accident and was taken to hospital. She was found to be in need of life-saving

⁴³ (1984) 469, 1052 NE2d at 1047.

⁴⁴ (1996) 671 NE 225, 229.

⁴⁵ [2002] EWHC 429. See paragraph 3.21.

⁴⁶ *Ibid* at 473.

⁴⁷ *Ibid* at 473.

⁴⁸ Michalowski “Trial and Error at the End of Life – No Harm Done?” (2007) 27(2) *Oxford Journal of Legal Studies* 257 at 265.

⁴⁹ (1990) 67 DLR (4th) 321.

transfusions, but a nurse found a signed card in her purse which stated that, as a Jehovah's Witness, she requested that no blood transfusions be administered to her. The treating physician was advised of the card but administered the life-saving blood transfusion. The Ontario Court of Appeal upheld Mrs Malette's claim for battery and awarded \$20,000 damages. The Court stated:

"A doctor is not free to disregard a patient's advance instructions any more than he would be free to disregard instructions given at the time of the emergency. The law does not prohibit a patient from withholding consent to emergency medical treatment, nor does the law prohibit a doctor from following his patient's instructions. While the law may disregard the absence of consent in limited emergency circumstances, it otherwise supports the right of competent adults to make decisions concerning their own health care by imposing civil liability on those who perform medical treatment without consent."⁵⁰

5.25 The Canadian approach appears to lean in the direction of stating that a competent person's wishes must be followed, and that if they are not, some civil law consequences will follow.

(iii) Wrongful Living Cause of Action

5.26 The reluctance of the US judiciary to recognise damages under traditional tort claims, such as negligence and battery, prompted the development of the "wrongful living" cause of action.⁵¹ A wrongful living cause of action involves a claim for damages for the harm of prolonged life resulting from the administration of life-sustaining treatment in violation of the patient's express wishes.⁵² Oddi first proposed the wrongful living cause of action in a

⁵⁰ (1990) 67 DLR (4th) 321 at 330.

⁵¹ Meisel *The Right to Die* (2nd ed New York: Wiley Law Publications 1995) at 401 cited in Donohue "Wrongful Living': Recovery for a Physician's Infringement on an Individual's Right to Die" (1997-1998) 14 *Journal of Contemporary Health Law and Policy* 391 at 394. See also Strasser "A Jurisprudence in Disarray: On Battery, Wrongful Living and the Right to Bodily Integrity" 36 (1999) *San Diego Law Review* 997; Peters "The Illusion of Autonomy at the End of Life: Unconsented Life Support and the Wrongful Life Analogy" (1998) 45 *UCLA Law Review* 673; Milani "Better off Dead than Disabled? Should Courts Recognise a 'Wrongful Living' Cause of Action When Doctors Fail to Honour Patients' Advance Directives?" 54 (1997) *Washington and Lee Law Review* 149; Oddi "The Tort of Interference with the Right to Die: The Wrongful Living Cause of Action" (1986) 75 *Georgetown Law Journal* 625.

⁵² A wrongful living cause of action should be distinguished from a wrongful life cause of action. The latter involves a claim by a child that they would not be living

law review article in 1986. Although he discussed possible actions based on traditional tort concepts, he ultimately identified a new tort:

“Whether the interfering treatment is conducted with or without due care is irrelevant, except insofar as such treatment prolongs the life of the individual contrary to the right to die. If the interfering treatment is made and the patient lives, then interference with the right to die involves compensation for living. This is a ‘wrongful living’ cause of action’.”⁵³

Donohue argues, however, that wrongful living is not in fact a separate cause of action, but a damages concept. Like a claim for ‘wrongful whiplash’ or a ‘wrongful broken arm’, it is an action involving an underlying claim of negligence or battery.⁵⁴

5.27 Despite the recognition of a constitutional right to refuse life-sustaining medical treatment in *Cruzan v Director, Missouri Department of Health*,⁵⁵ a wrongful living cause of action for violating this right has not gained widespread acceptance in the United States as courts are reluctant to recognise the prolongation of life as an injury entitling the plaintiff to damages. Courts and legal theorists have rejected the wrongful living cause of action for a number of reasons. In *Anderson v St Francis-St George’s Hospital*,⁵⁶ the Supreme Court of Ohio expressly held that no cause of action exists for wrongful living in the state of Ohio,⁵⁷ quoting from prior wrongful living opinions in which it had both “recognised ‘the impossibility of a jury placing a price tag’ on the benefit of life”,⁵⁸ and also “disapproved of awarding damages on the relative merits of

but for someone else’s fault. See Morris and Santier “To Be or Not To Be: Is That The Question? Wrongful Life and Misconceptions” (2003) 11 *Medical Law Review* 167.

⁵³ Oddi “The Tort of Interference with the Right to Die: The Wrongful Living Cause of Action” (1986) 75 *Georgetown Law Journal* 625 at 661.

⁵⁴ Donohue “‘Wrongful Living’: Recovery for a Physician’s Infringement on an Individual’s Right to Die” (1997-1998) 14 *Journal of Contemporary Health Law and Policy* 391 at 399.

⁵⁵ (1990) 497 US261.

⁵⁶ (1996) 971 NE 225.

⁵⁷ *Ibid* at 228.

⁵⁸ (1996) 671 NE 225 at, 228 quoting *Johnson v University Hospital of Cleveland* (1989) 540 NE2d 1370 at 1378.

'being versus non-being'.⁵⁹ In *Smith v Cote*,⁶⁰ the New Hampshire Supreme Court held that to legally recognise that a disabled life is an injury would harm the interests of disabled persons who must face the attitudes and behaviours of society, the law and their families who may view them as "burdensome misfits." The Court noted that recent legislation concerning employment, education and building access reflects the slow change in these attitudes. The Court went on to note that this change evidences a growing public awareness that the disabled "can be valuable and productive members of society." The Court concluded that to "characterise the life of a disabled person as an injury would denigrate both this new awareness" and the person themselves.⁶¹

5.28 It has also been contended that there are adequate remedies available under tort law without having to establish a new cause of action. For example, Pedrick has maintained that "when health care givers subject a competent patient to life sustaining procedures against his or her will, the settled law of torts provides a remedy by way of an action for battery, with resultant liability on the part of health care givers for substantial damages, both general and punitive."⁶² However, while the interference with the right to refuse medical treatment gives rise to a claim in damages in theory under negligence and battery, plaintiffs have encountered judicial resistance in practice.⁶³

(iv) Wrongful life cause of action

5.29 A wrongful life cause of action involves a claim by a child that they would not be living but for someone else's fault. Life itself is said to be the injury.⁶⁴ The issue arose in England in *McKay v Essex Area Health Authority*⁶⁵. During her pregnancy Mrs McKay contracted rubella but it was not diagnosed. Had she been aware, Mrs McKay would have had an abortion. As a result of the

⁵⁹ (1996) 671 NE 225, 228 quoting *Bowman v Davis* (1976) 356 NE 2d 496 at 499 n3.

⁶⁰ 513 A2d 341 (NH 1986).

⁶¹ 513 A2d 341, 353 (NH 1986) cited in Milani "Better off Dead than Disabled? Should Courts Recognise a 'Wrongful Living' Cause of Action When Doctors Fail to Honour Patients' Advance Directives?" (1997) 54 *Washington and Lee Law Review* 149 at 219.

⁶² Pedrick "Dignified Death and the Law of Torts" (1991) 28 *San Diego Law Review* 387 at 396.

⁶³ See paragraphs 5.15 and 5.20 on negligence and battery above.

⁶⁴ Morris and Saintier, "To Be or Not to Be: Is That The Question? Wrongful Life and Misconceptions" (2003) 11 *Medical Law Review* 167 at 167.

⁶⁵ [1982] 2 All ER 771.

rubella, her child was born with a disability. It was claimed that the defendants were negligent in allowing the child to be born. During the English Court of Appeal decision, Stephenson LJ felt that to determine that the unborn child had a right to die would lead to the conclusion that the life of a child with a disability was of such lesser value than any other child that it was not worth preserving.⁶⁶

5.30 Stephenson LJ indicated that there is no difference between the quality and quantity of life. It was felt that the court was ill equipped to compare “the injured child’s life in this world and determine that the child has lost anything, without knowing what, if anything the child has gained”.⁶⁷ Stephenson LJ went on to state that “[i]f a court had to decide whether it were better to enter into life maimed or halt than not to enter at all, it would, I think, be bound to say it was better in all cases of mental and physical disability”.⁶⁸

5.31 The Law Commission for England and Wales recommended that there should not be an action for wrongful life.⁶⁹ The Commission reasoned that it would be impossible to “argue that the child would have been better off had it never existed.”⁷⁰

5.32 While not widely accepted, the cause of action for wrongful life has received some recognition in the United States. In *Turpin v Sortini*⁷¹ the parents in question had a second child when the defendants wrongfully told them that their first child did not suffer from hereditary deafness. The child, who was also deaf, brought a wrongful life action. While the court did allow the plaintiffs claim for extraordinary expenses, general expenses were denied as the court could not determine whether an injury was suffered at all.⁷² However the court did note that while the sanctity of life is important, it could not be assumed “that impaired life is preferable to non-life”.⁷³

⁶⁶ *Ibid* at 781.

⁶⁷ *Ibid* at 782.

⁶⁸ *Ibid*.

⁶⁹ Law Commission *Report on Injuries to Unborn Children* No 60 HMSO 1974 cmnd 5709 at 34.

⁷⁰ *Ibid*.

⁷¹ (1982) 182 Cal Rptr 337.

⁷² *Ibid*.

⁷³ *Ibid*.

(v) Infliction of emotional suffering

5.33 A person may be guilty of a tort where he or she intentionally or recklessly inflicts emotional suffering on another.⁷⁴ In *Wilkinson v Downton*⁷⁵, the defendant, as a practical joke, told the plaintiff that her husband had been injured and that she was to go to him immediately. Although the action did not fit easily into any established categories, liability was imposed on the basis that the defendant had:

“wilfully done an act calculated to cause physical harm to the plaintiff, that is to say, to infringe her legal right to personal safety, and has in fact thereby caused physical harm to her. That proposition without more appears to me to state a good cause of action, there being no justification alleged for the act. The wilful *injuria* is in law malicious, although no malicious purpose to cause the harm which was caused, nor any motive of spite is imputed to the defendant.”⁷⁶

5.34 In the United States, the tort is considerably more developed. It is committed where the defendant by extreme and outrageous conduct intentionally or recklessly causes severe emotional distress to another.⁷⁷ In *Perkins v Lavin*,⁷⁸ a Jehovah’s Witness had executed an advance care directive in the form of a written release, specifically stating that she did not wish to receive any blood products or transfusions during a surgical procedure and absolving both her doctor and hospital from liability in such an event. However, her doctor administered a blood transfusion as a life-saving measure due to surgical complications. The plaintiff sued intentional infliction of emotional distress. In order to recover on the latter basis in Ohio, a plaintiff must establish the provider’s intent to cause serious emotional distress, extreme and outrageous conduct that exceeds “all possible bounds of decency” and causation.⁷⁹ The Ohio Court of Appeals chose, however, to examine the doctor’s conduct in light of the “average member of the community” and held it to be reasonable. It has been argued that to view the conduct element of this

⁷⁴ See Mc Mahon and Binchy at paragraphs 22.28-22.34.

⁷⁵ [1897] 2 QB 57.

⁷⁶ *Ibid* at 58-59 per Wright J.

⁷⁷ *Restatement, Second, On Torts* (American Law Insitute,1964) at 846.

⁷⁸ *Perkins v Lavin* (1994) 648 NE 2d 840.

⁷⁹ Tyminski “The Current State of Advance Directive Law” (2004-2005)19 *Journal of Law and Health* 411 at 439 citing *Anderson v St Francis Hospital* (1996) 671 NE 2d 225 at 229 and *Roelen v Akron Beacon Journal* (2002) 199 F Supp 2d 685.

cause of action in light of the average member of the community “deemphasizes the very personal right to refuse medical treatment.”⁸⁰

(vi) Damages

(I) Nominal Damages

5.35 Nominal damages may be awarded where the plaintiff’s legal right has been infringed, but he or she has suffered no actual damage.⁸¹ The plaintiff’s purpose in bringing the action may have been to vindicate a right rather than to seek substantial compensation as was the case in *B v An NHS Trust*.⁸² There, Butler-Sloss P awarded £100 to be paid by the NHS Trust to Ms B who had repeatedly requested the removal of ventilation for a number of months. However, as Michalowski notes, her physicians escaped all liability despite having blatantly disregarded her wishes and having knowingly committed an ongoing battery. She argues that the nominal sum of £100 neither provides adequate compensation for the patient nor acts as a convincing deterrent for future violations of the law.⁸³

(II) General Damages

5.36 In *Malette v Shulman*, the Ontario Court of Appeal awarded general damages of €20,000.⁸⁴ Although Robins JA stressed that the treatment was competent, that the results were favourable, that the doctor’s overall conduct was exemplary and that he acted in good faith, he concluded that Mrs Malette had suffered mentally and emotionally by reason of the battery and that such injuries were compensable. In *Re T*,⁸⁵ although Butler-Sloss LJ cited *Malette* with approval, she did not consider that an English court would award damages

⁸⁰ Tyminski “The Current State of Advance Directive Law” (2004-2005)19 *Journal of Law and Health* 411 at 441.

⁸¹ McMahon and Binchy *Law of Torts* (3rd ed Butterworths 2000) at paragraph 44.03 citing *O’Keefe v Kulcullen* High Court (O’Sullivan J) 24 June 1998: “Nominal damages means a sum of money that may be spoken of but has no existence in point of quantity, the purposes of such damages being twofold, namely, either to assert a right or as a ‘peg’ on which to hang an order for costs.”

⁸² [2002] EWHC 429.

⁸³ Michalowski “Trial and Error at the End of Life – No Harm Done?” (2007) 27(2) *Oxford Journal of Legal Studies* 257 at 265.

⁸⁴ (1990) 67 DLR (4th) 321. See the discussion at paragraph 5.24 above. See Michalowski “Trial and Error at the End of Life – No Harm Done?” (2007) 27(2) *Oxford Journal of Legal Studies* 257 at 266.

⁸⁵ [1992] 4 All ER 649.

in similar circumstances.⁸⁶ Staughton LJ observed that he doubted that an English court would have awarded such a high sum, but confirmed that some liability would exist.⁸⁷

(III) Special Damages

5.37 A possible solution to mitigate judicial reluctance to award general damages for the violation of the right to refuse medical treatment is to allow only special damages for the medical expenses and extraordinary costs incidental to the plaintiff's continued living.⁸⁸ Special damages have been awarded in wrongful life claims. In *Procanik v Cillo*,⁸⁹ the New Jersey Supreme Court limited recovery to special damages in the case of a physician who negligently failed to diagnose measles during the first trimester of pregnancy. In so doing, the court avoided having to recognise life as a legally recognisable harm, which would be required in a finding for general damages for a child's pain and suffering. The court observed that "the interests of fairness and justice are better served through more predictably measured damages – the costs of the extraordinary medical expenses necessitated by the infant child's handicaps."⁹⁰ It is argued that special damages for wrongful living would be easier to assess than those for wrongful life, as the former involves a very precise time frame commencing with the refused treatment, and concluding with the patient's death whereas the latter involves the lifetime of a child.⁹¹

(vii) Wrongful interference with constitutional rights

(I) Constitutional rights are enforceable against private individuals as well as the State

5.38 There is a constitutional right to refuse medical treatment under Irish law. The Irish courts have held that a constitutional right in one person implies a corresponding duty in, not only the State, but also in other persons to respect

⁸⁶ [1992] 4 All ER 649at 665 per Butler-Sloss LJ.

⁸⁷ *Ibid* at 669 per Staughton LJ.

⁸⁸ Donohue "Wrongful Living': Recovery for a Physician's Infringement on an Individual's Right to Die" (1997-1998) 14 *Journal of Contemporary Health Law and Policy* 391 at 413.

⁸⁹ 478 A 2d 755 (NJ 1984).

⁹⁰ *Ibid* at 763.

⁹¹ Donohue "Wrongful Living': Recovery for a Physician's Infringement on an Individual's Right to Die" (1997-1998) 14 *Journal of Contemporary Health Law and Policy* 391 at 415-416.

that right.⁹² In *Educational Company of Ireland Ltd v Fitzpatrick (No 1)*,⁹³ Ó Dálaigh CJ stated:

“Liberty to exercise a right, it seems to me, prima facie implies a correlative right on others to abstain from interfering with the exercise of such right.”⁹⁴

Therefore, if a person wrongfully interferes with the exercise of another’s constitutional right, it amounts to a civil wrong for which the courts will provide a remedy.⁹⁵ In *Meskeil v CIE*,⁹⁶ Walsh J stated:

“[I]f a person has suffered damage by virtue of a breach of a constitutional right or the infringement of a constitutional right, that person is entitled to seek redress against the person or persons who have infringed that right.”⁹⁷

More recently, and more importantly for the purposes of this Consultation Paper, Denham J acknowledged in *Re a Ward of Court (No 2)*,⁹⁸ that the right to bodily integrity must be recognised by private individuals as well as by the State.

(II) *Claims for damages*

5.39 In *W v Ireland (No 2)*,⁹⁹ Costello P conducted a detailed analysis on the issue of compensation for infringement of constitutional rights. He stated that constitutionally guaranteed rights may be divided into two distinct classes – constitutionally guaranteed rights which are regulated and protected by law (common law or statute), independently of the Constitution, and those that are not so regulated and protected. In the first class of rights are all those fundamental rights which the Constitution recognised that a person has by virtue of his or her rational being antecedent to positive law and were rights regulated and protected by law in every State which values human rights. In

⁹² See Hogan and Whyte *JM Kelly: The Irish Constitution* (4th ed LexisNexis Butterworths 2003) at paragraphs 7.1.101-7.1.108; McMahon and Binchy *Law of Torts* (3rd ed Butterworths 2000) at paragraphs 1.09-1.83.

⁹³ [1961] IR 323.

⁹⁴ *Ibid* at 343.

⁹⁵ Sometimes referred to as a ‘constitutional tort’.

⁹⁶ [1973] IR 121.

⁹⁷ *Ibid* at 133.

⁹⁸ [1996] 2 IR 79 citing *The People (DPP) v JT* (1988) 3 Frewen 141 in support.

⁹⁹ [1997] 2 IR 141.

Ireland, there existed a large and complex body of laws which regulated the exercise and enjoyment of these basic rights, protected them against attack and provided compensation for their wrongful infringement.¹⁰⁰ For example, in the present case, which was a case concerning a claim for physical and sexual abuse, the right of bodily integrity was protected by extensive provisions in the law of tort, and therefore the Constitution did not confer a discrete cause of action for damages for its breach.¹⁰¹

5.40 With regard to the second class of rights, Costello P noted that it was well established that the Constitution was to be interpreted as providing a separate cause of action for damages for breach of a constitutional right: in *Meskill v CIE*,¹⁰² *Kearney v Minister for Justice*,¹⁰³ *McHugh v Commissioner of An Garda Síochána*¹⁰⁴ and *Kennedy v Ireland*,¹⁰⁵ damages were awarded for breaches of guaranteed constitutional rights where no remedies for damages existed by common law or by statute. Similarly in the case of *Lovett v Gogan*,¹⁰⁶ the Supreme Court granted an injunction to protect the plaintiff from the threatened invasion of his constitutional right to earn a living by lawful means. Given judicial reluctance not only to accept the prolongation of life as a harm in the traditional torts of battery and negligence, but also to acknowledge the tort of wrongful living, a plaintiff might be able to claim damages for a breach of his or her constitutional right to refuse treatment.

(4) Professional Regulation

5.41 Although no damages were granted to Mr Winter's estate in *Anderson v St Francis-St George's Hospital*,¹⁰⁷ the Supreme Court of Ohio did warn that "unwanted life-saving treatment does not go undeterred" and that appropriate licensing sanctions against the medical professionals responsible were appropriate.¹⁰⁸ Disciplinary sanctions, while not serving the same

¹⁰⁰ [1997] 2 IR 141 at 164.

¹⁰¹ *Ibid* at 165. Costello P did accept, *obiter*, that where the existing law did not adequately protect the guaranteed right, then the law would be applied without the provision, which would be rendered invalid by the Constitution.

¹⁰² [1973] IR 121.

¹⁰³ [1986] IR 116.

¹⁰⁴ [1986] IR 228.

¹⁰⁵ [1987] IR 587.

¹⁰⁶ [1995] 1 ILRM 12.

¹⁰⁷ (1996) 671 NE 225.

¹⁰⁸ (1996) 671 NE 225 at 227.

purposes as tort law, may still serve as a useful tool to prevent violations of patient autonomy.¹⁰⁹

5.42 In Ireland, section 57 of the *Medical Practitioners Act 2007* states that any person (including the Council) can make a complaint to the Preliminary Proceedings Committee (PPC) concerning a registered medical practitioner on the ground, *inter alia*, of professional misconduct.¹¹⁰ No statutory definition is given in the 2007 Act of 'professional misconduct'. Nevertheless, guidance can be gleaned from cases such as *O'Laoire v Medical Council*,¹¹¹ in which Keane J set out four tests for establishing professional misconduct, the last of which may be the most 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.”¹¹²

Section 71 of the 2007 Act states that the Medical Council has the power, on receiving a report from the Fitness to Practice Committee (FCC), 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;

¹⁰⁹ Michalowski “Trial and Error at the End of Life – No Harm Done?” (2007) 27(2) *Oxford Journal of Legal Studies* 257 at 280.

¹¹⁰ For the position under the *Medical Practitioners Act 1978* which the 2007 Act repealed see Kennedy “How the Medical Council Sanctions Doctors – Part V of the Medical Practitioners Act 1978” 11(2) *Medico-Legal Journal of Ireland* 63 at 68. See also Mills *Clinical Practice and the Law* (2nd ed Tottel Publishing 2007) at paragraphs 2.37-2.65; Kelly and O’Shea “The Medical Practitioner’s Act 2007 – An Overview” (2007) 13(2) *Medico-Legal Journal of Ireland* 63.

¹¹¹ High Court (Keane J) 27 January 1995 109. See also Mills *Clinical Practice and the Law*, 2nd ed (Tottel, 2007) at paragraph 2.57.

¹¹² This test was included in the definition of professional misconduct in the most recent edition of the Medical Council’s *A Guide to Ethical Conduct and Behaviour* (6th ed 2004) at paragraph 1.5.

- (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."

5.43 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.¹¹³

C Statutory framework for implementation of advance care directives

(1) Ireland

5.44 As the Commission has already noted, there is no current statutory framework in Ireland for advance care directives. In this Part, the Commission discusses below the extent to which liability concerning advance care directives has arisen in statutory schemes in other States. Before turning to those models, the Commission draws attention to a statutory model in a medical setting that contains some elements of note. The *Control of Clinical Trials Act 1987*, as amended by the *Control of Clinical Trials and Drugs Act 1990*, provides a statutory framework under which clinical trials are regulated in the State. For the purposes of this Consultation Paper, the essential feature of the 1987 Act is that, where a clinical trial conforms to the statutory model it sets out, no criminal liability can arise for health care professionals. In addition, a number of features of the 1987 Act are worthy of note in the context of a criminal prosecution against a health care professional:

- it is a defence for the health care professional to assert that he or she acted with due diligence;¹¹⁴
- it is a defence for the health care professional to show that any substances or preparation were administered for the purpose of providing emergency medical or dental treatment;¹¹⁵ and

¹¹³ Section 74 of the *Medical Practitioners Act 2007*.

¹¹⁴ Section 13(2)(b) of the *Control of Clinical Trials Act 1987*.

- the 1987 Act contains a presumption concerning the harmful effect of any substances or preparation administered.¹¹⁶

5.45 It is clear that some of these features of the 1987 Act are specific to the context of clinical trials, but they provide some useful elements which might be included in a statutory scheme for advance care directives.

(2) England and Wales

(a) Mental Capacity Act 2005

5.46 In its 1995 Report, the Law Commission of England and Wales made two recommendations with regard to the liability of health care providers.¹¹⁷ First, it recommended that no person should incur liability for the consequences of withholding any treatment or procedure if he or she has reasonable grounds for believing that an advance refusal of treatment applies. It noted that although this was the present law, the importance of the rule was such that it should be set out in the proposed statute. Second, it recommended that no person should incur liability for carrying out any treatment or procedure to which an advance refusal applies unless he or she has reasonable grounds for believing that an advance refusal applies.

5.47 At first glance, section 26 of the English *Mental Capacity Act 2005* appears to incorporate both recommendations of the Law Commission. Section 26(3) states that:

“ a person does not incur liability for the consequences of *withholding or withdrawing* a treatment from [the maker of the decision] if, at the time, he *reasonably believes* that an advance decision exists which is valid and applicable to the treatment.”¹¹⁸

In a similar vein, section 26(2) of the 2005 Act states that:

“a person does not incur liability for *carrying out or continuing* the treatment unless, at the time, he is *satisfied* that an advance decision exists which is valid and applicable to the treatment.”¹¹⁹

¹¹⁵ Section 13(1)(b) of the *Control of Clinical Trials Act 1987*.

¹¹⁶ Section 14 of the *Control of Clinical Trials Act 1987*.

¹¹⁷ The Law Commission for England and Wales *Report on Mental Incapacity* (No 231 1995) at paragraph 5.27.

¹¹⁸ Emphasis added. See also *Mental Capacity Act 2005 – Code of Practice* at paragraph 9.59.

¹¹⁹ Emphasis added.

The most obvious difference between the sections is that section 26(3) refers to negative action (the withdrawing or withholding of treatment) while section 26(2) refers to positive action (carrying out or continuing the treatment). On closer inspection, section 26(3) requires that a healthcare professional's belief as to the existence, validity and applicability of an advance decision must be "reasonable", whereas section 26(2) merely requires that a healthcare professional must be "satisfied." Given the explicit reference to "reasonable" in section 26(3), it has been argued that it is unlikely that the courts will interpret section 26(2) as implicitly requiring the professional's satisfaction to be reasonable.¹²⁰ The omission of reasonableness from section 26(2) has led to criticism that it gives professionals "considerable discretion" and makes any advance decision "inherently more vulnerable."¹²¹

(b) Code of Practice for 2005 Act

5.48 The Code of Practice for the 2005 Act notes that healthcare professionals have a number of responsibilities.¹²² First, they should be aware that a patient may have refused treatment in advance, and that valid and applicable advance decisions to refuse treatment have the same legal status as contemporaneous medical decisions. Second, where appropriate, healthcare professionals should ask patients with capacity if there are any specific types of treatment they do not wish to receive if they ever lack capacity to consent in the future. Third, if a healthcare professional is told that an advance decision exists, they should make reasonable efforts to find out what the decision is.¹²³

5.49 The most important (and perhaps onerous) responsibility facing health care professionals is that they must determine whether an advance decision is valid and applicable once they are aware that it exists. Healthcare professionals must follow an advance directive if they are satisfied that it exists, is valid and is applicable to their circumstances. Otherwise, they may be liable in battery or assault.¹²⁴ When establishing whether an advance decision applies to current circumstances, healthcare professionals should take care if the decision does not seem to have been reviewed or updated for some time.

¹²⁰ McLean "Advance Directives and the Rocky Waters of Anticipatory Decision-Making" (2008) 16(1) *Medical Law Review* 1 at 21.

¹²¹ *Ibid.*

¹²² *Mental Capacity Act 2005 – Code of Practice* at paragraphs 9.47-9.54.

¹²³ *Mental Capacity Act 2005 – Code of Practice* at paragraph 9.49. Reasonable efforts include having discussions with relatives of the patient, looking in the patient's clinical notes held in the hospital or contacting the patient's GP.

¹²⁴ *Mental Capacity Act 2005 – Code of Practice* at paragraph 9.57.

The Code of Practice cites a number of situations that might be enough in themselves to raise concern about the existence, validity or applicability of an advance decision to refuse treatment:

- “A disagreement between relatives and healthcare professionals about whether verbal comments were really an advance decision;
- Evidence about the person’s state of mind raises questions about their capacity at the time they made the decision;
- Evidence of important changes in the person’s behaviour before they lost capacity that might suggest a change of mind.”¹²⁵

5.50 In any event it is notable that the English 2005 Act does not provide for any explicit sanction for failure to comply with an advance care directive. In this respect, the Code of Practice for the 2005 Act draws attention to potential liability at common law for assault and battery. In this respect, the Commission notes that Head 16 of the Government’s *Scheme of Mental Capacity Bill 2008*, published in September 2008, states that where a compliance with its terms, this does not exclude possible civil or criminal liability.

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

(3) Australia

(a) Separate offence for failure to follow an advance care directive

5.52 By contrast with the approach in the English 2005 Act, the Australian jurisdictions of Victoria and Queensland¹²⁶ have created separate criminal offences for failure to follow an advance care directive. For example, section 6 of the *Medical Treatment Act 1988* (Vic) states that an offence of medical trespass is committed when a registered medical practitioner, knowing that a refusal of treatment certificate applies to a person, undertakes or continues to undertake any medical treatment to which the certificate applies.

(b) Disregarding a lawful advance care directive

(i) Disregarding an advance care directive because health care professional is unaware that advance care directive exists

5.53 In Queensland, section 102 of the *Powers of Attorney Act 1998 (Qld)* states that:

¹²⁵ *Mental Capacity Act 2005 – Code of Practice* at paragraph 9.60.

¹²⁶ Section 79 of the *Guardianship and Administration Act 2000 (Qld)*.

“A health provider is not affected by an adult’s advance health directive to the extent the health provider does not know the adult has an advance health directive.”

There is a lack of clarity regarding the meaning of the word ‘know’. It is unclear whether the term is restricted to actual knowledge or whether it should be extended to imputed knowledge or even wilful blindness.¹²⁷

(ii) *Disregarding an advance care directive because health care professional is unaware that advance care directive is invalid*

5.54 Section 100 of the *Powers of Attorney Act 1998 (Qld)* provides that a health provider who relies on an invalid advance health directive will be protected, if he or she does not know of the invalidity at the time he or she acts in reliance on the directive. Neither the terms ‘invalidity’ nor ‘knowing’ are defined in the legislation.

(iii) *Disregarding an advance care directive because of change in circumstances*

5.55 Section 103(1) of the *Powers of Attorney Act 1998 (Qld)* provides that a health care professional does not incur any liability for failing to follow a directive if he or she has:

“reasonable grounds to believe that...circumstances, including advances in medical science, have changed to the extent that the terms of the direction are inappropriate.”

This provision has considerable flexibility, as it has the power to embrace changes in an adult’s religious beliefs (as was the case in *HE v A Hospital NHS Trust*),¹²⁸ advances in medical science, and the situation in which an adult has changed his or her mind about an advance directive, but fails to revoke it.¹²⁹ Some commentators have argued that this statutory excuse is too broad and that the focus of the enquiry is wrongly shifted towards the health care professional.¹³⁰ For example, the test that is applied at common law is whether

¹²⁷ White and Willmott *Rethinking Life-Sustaining Measures: Questions for Queensland: An Issues Paper Reviewing the Legislation Governing Withholding and Withdrawing Life-Sustaining Measures (QUT 2005)* at 42-44.

¹²⁸ Discussed in paragraph 4.70 above.

¹²⁹ However, this situation is dealt with specifically in certain Australian statutes. See paragraph on intention to revoke.

¹³⁰ Willmott, White and Howard “Refusing Advance Refusals: Advance Directives and Life-Sustaining Medical Treatment” (2006) 30 *Melbourne University Law Review* 211 at 230.

the change in circumstances is such that the *adult* would not have intended his or her refusal to apply to the circumstances that have arisen.¹³¹ Section 103(1) of the 1998 Queensland Act asks, however, whether a *health care professional* has reasonable grounds to believe that there is a change in circumstances that renders the advance directive inappropriate. In the Commission's view, the common law position is to be preferred, as its approach strikes a "more sensible balance between principles of autonomy and the sanctity of life."¹³²

5.56 Victoria's legislation is more limited, in that it focuses on a change in circumstances relating to an adult's medical condition. Section 7(3) of the *Medical Treatment Act 1988* (Vic) states that a directive will no longer apply:

"if the medical condition of the person has changed to such an extent that the condition in relation to which the [advance directive] was given is no longer current."

(iv) *Disregarding an advance care directive if it is uncertain*

5.57 Difficulties with advance care directives can often arise when language is vague or imprecise. For example, the case of *W Healthcare NHS Trust v H*¹³³ involved statements that referred to a "reasonable quality of life." In Queensland, section 103(1) of the *Powers of Attorney Act 1998* (Qld) excuses a health care professional if he or she has "reasonable ground to believe that a direction in an [advance directive] is uncertain." Although "uncertainty" is not defined, section 103(3) of the 1998 Act states:

"if an attorney is appointed under the [advance care directive], the [health professional] has reasonable grounds to believe that a direction in the [advance care directive] is uncertain only, if, among other things, the [health professional] has consulted the attorney about the direction."

Section 103(3) merely requires a health care professional to consult an attorney in order to clarify or explain the advance directive. It does not require the health care professional to accept that clarification or explanation. There is also the

¹³¹ Wilmott, White and Howard "Refusing Advance Refusals: Advance Directives and Life-Sustaining Medical Treatment" (2006) 30 *Melbourne University Law Review* 211 at 230 citing Michalowski "Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right" (2005) 68(6) *Modern Law Review* 958 at 979.

¹³² Wilmott, White and Howard "Refusing Advance Refusals: Advance Directives and Life-Sustaining Medical Treatment" (2006) 30 *Melbourne University Law Review* 211 at 230.

¹³³ [2005] 1 WLR 834. See paragraph 3.46 above.

danger that the more uncertain a directive is, the more likely it is that an attorney will make their own decision, albeit based on what he or she thinks the maker of the advance directive would have wanted.¹³⁴

(v) *Disregarding an advance care directive if it is contrary to good medical practice*

5.58 The English *Mental Capacity Act 2005* states that a medical professional does not have to do something against their beliefs.¹³⁵ A medical professional can therefore disagree with a patient's decision to refuse life-sustaining medical treatment.

5.59 Similarly, the Irish Medical Council's ethical guidelines also state 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".¹³⁶ Fennan argues that

"One option would be to include in any legislation (or code of practice) a provision which, while allowing a doctor to exercise a conscientious objection to personally withdrawing treatment, would state that this would not eclipse the doctor's duty to refer the patient, if practicable, to another doctor or facility willing to carry out this lawful action".¹³⁷

5.60 Queensland is the only Australian jurisdiction in which a health professional is excused from following a valid advance care directive for reasons grounded in good medical practice. Section 103(1) of the *Powers of Attorney Act 1998* (Qld) provides that a health professional does not incur any liability for failing to follow a directive if he or she has "reasonable grounds to believe that a direction in an [advance care directive] is...inconsistent with good medical practice." 'Good medical practice' is defined as:

"...good medical practice for the medical profession in Australia having regard to –

(a) the recognised medical standards, practices and procedures of the medical profession in Australia; and

¹³⁴ Wilmott, White and Howard "Refusing Advance Refusals: Advance Directives and Life-Sustaining Medical Treatment" (2006) 30 *Melbourne University Law Review* 211 at 232.

¹³⁵ Bartlett *Blackstone's Guide to the Mental Capacity Act 2005*, 2nd edition (Oxford University Press, 2008) at 9.62.

¹³⁶ *Ibid* at paragraph 2.6.

¹³⁷ Medical Council *A Guide to Ethical Behaviour and Conduct*, 6th edition, 2004.

(b) the recognised ethical standards of the medical profession in Australia.”¹³⁸

This statutory excuse permits a health professional some discretion. A health professional is not prohibited from following an advance care directive that is inconsistent with good medical practice; rather, it simply excuses a health professional who chooses to ignore it.¹³⁹ This excuse has been heavily criticised and its repeal has been called for on the basis that it “seriously weakens the essence of advance directives: the ability of an adult to choose the treatment that he or she wishes to refuse, even if others may disagree.”¹⁴⁰

(4) Conclusions

5.61 If a medical professional refuses to follow the advance care directive, the autonomy of the patient is affected. The purpose of an advance care directive is to ensure that a patient retains autonomy over the future medical treatments and that their wishes are followed.

5.62 Should consequences flow from a medical professional’s intentional or negligent refusal to follow an advance care directive? Veatch submits that:

“It competent patients have a valid moral and legal right to refuse medical treatment, it stands to reason that they should have some recourse if they are treated against their consent. Real harms are incurred...Patients suffer physical pain...Hospital bills will have to be paid.”¹⁴¹

Indeed one could go as far as to say that without a legal remedy, there is no actual right to refuse medical treatment.¹⁴²

5.63 Can a medical professional be liable, however, for keeping a patient alive? The Medical Council’s Ethical Guidelines state that a competent patient’s

¹³⁸ Schedule 2 of the *Powers of Attorney Act 1998* (Qld).

¹³⁹ Wilmott, White and Howard “Refusing Advance Refusals: Advance Directives and Life-Sustaining Medical Treatment” (2006) 30 *Melbourne University Law Review* 211 at 235.

¹⁴⁰ *Ibid.*

¹⁴¹ Veatch “Foregoing Life-Sustaining Treatment: Limits to the Consensus”, (1993) 3 *Kennedy Inst Ethics Journal* 1 at 6.

¹⁴² Robb, “Living Wills: The Right to Refuse Life-Sustaining Medical Treatment - A Right Without a Remedy?” (1997) 23 *Dayton Law Review* 169.

refusal of treatment must be respected,¹⁴³ so that a refusal to follow a valid advance care directive could constitute professional misconduct.

5.64 Due to the ethical issues involved in following an advance care directive, the Commission invites submissions on whether consequences and sanctions should follow if a medical professional fails to follow a valid and applicable advance care directive.

5.65 *The Commission invites submissions on whether consequences and sanctions should follow if a medical professional fails to follow a valid and applicable advance care directive.*

¹⁴³ Medical Council *A Guide to Ethical Behaviour and Conduct*, 6th edition, 2004.

CHAPTER 6 SUMMARY OF PROVISIONAL RECOMMENDATIONS

6.01 The Commission’s provisional recommendations in this Consultation Paper may be summarised as follows:

6.02 The Commission provisionally recommends that the term “Advance Care Directive” be adopted. [Paragraph 1.18]

6.03 The Commission provisionally recommends that negative advance care directives only should be regarded as legally binding. [Paragraph 1.32]

6.04 An advance care directive is an advance indication of a person’s wishes that certain medical care is not to be given in the event that the patient becomes incompetent. [Paragraph 1.33]

6.05 The Commission invites submissions on the status of “Do Not Resituate” (DNR) orders. [Paragraph 1.47]

6.06 The Commission provisionally recommends that an advance care directive cannot refuse actions concerning basic care. [Paragraph.1.52]

6.07 The Commission provisionally recommends that a healthcare proxy may be appointed in an advance care directive. The functions of the healthcare proxy should include:

- Ensuring that the wishes as expressed by the author of the advance care directive are followed.
- Consultation with the medical professional if there is any ambiguity in the advance care directive. [Paragraph 1.65]

6.08 The Commission provisionally recommends that advance care directives be placed on a statutory footing. The Commission provisionally recommends that a set of guidelines be drawn up to complement the legislative framework. [Paragraph 2.48]

6.09 The Commission provisionally recommends that a refusal to consent to treatment on religious grounds will in general (subject to constitutional considerations) constitute a valid advance care directive. [Paragraph 2.64]

6.10 The Commission provisionally recommends that makers of advance care directives should be encouraged to consult with a medical professional

when making an advance care directive. In the case of advance care directives refusing life-sustaining medical treatment, the Commission provisionally recommends that medical advice must be obtained for the advance care directive to be valid. [Paragraph 3.15]

6.11 The Commission provisionally recommends that there is a rebuttable presumption of capacity in favour of the maker of an advance care directive. [Paragraph 3.34]

6.12 The Commission provisionally recommends that the capacity to refuse healthcare decisions should be assessed on the functional test of capacity. The Commission also provisionally recommends that the statutory codes of practice be formulated to guide healthcare professionals when assessing the capacity of an individual. [Paragraph 3.35]

6.13 The Commission invites submissions on the age a person must be before they can make a valid advance care directive. [Paragraph 3.52]

6.14 The Commission provisionally recommends that both oral and written advance care directives are valid. [Paragraph 4.13]

6.15 In the case of life-sustaining treatment, the Commission provisionally recommends that only written advance care directives are valid. The Commission invites submissions on the definition of life-sustaining medical treatment and on whether artificial nutrition and hydration is life-sustaining medical treatment. [Paragraph 4.23]

6.16 The Commission provisionally recommends that only a written advance care directive which refuses life-sustaining medical treatment must be witnessed by at least one person. [Paragraph 4.33]

6.17 The Commission provisionally recommends that it is not necessary for an advance care directive to be in a prescribed form. [Paragraph 4.37]

6.18 The Commission provisionally recommends that an advance care directive will not be valid if

- The author of the advance care directive did not have 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
- If a written advance care directive refusing life-sustaining medical treatment was not witnessed and if the person did not consult with a medical professional [Paragraph 4.61]

6.19 The Commission provisionally recommends that an advance care directive is not applicable if

- It is ambiguous in relation to the proposed treatment
- If all the circumstances outlined in the advance care directive are 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 author had changed their mind but did not have the opportunity to revoke the advance care directive. [Paragraph 4.62]

6.20 The Commission provisionally recommends that before an advance care directive is activated, the author of the advance care directive must lack capacity and the treatment proposed must be the treatment outlined in the advance care directive. [Paragraph 4.68]

6.21 The Commission provisionally recommends that a competent person can verbally revoke their advance care directive regardless of whether there is a verbal or written advance care directive and also welcomes submissions on this point. [Paragraph 4.78]

6.22 The Commission provisionally recommends that, while advance care directives should be reviewed regularly, there should be no time limit put on their validity. [Paragraph 4.84]

6.23 The Commission invites submissions on whether it is necessary to have a central filing system for advance care directives. [Paragraph 4.88]

6.24 The Commission provisionally 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 5.51]

6.25 The Commission invites submissions on whether consequences and sanctions should follow if a medical professional fails to follow a valid and applicable advance care directive. [Paragraph 5.65]



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.

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The Law Reform Commission is a statutory body established by the Law Reform Commission Act 1975