# Advance Care Directives and Medical Treatment Decision-Making:

# Preserving Patient Autonomy

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*Abstract*

The principle of autonomy allows each person control over his or her body, and, consequently, to decide what medical treatment he or she will accept or refuse. However, where the individual does not have the ability, or capacity, to make such a decision, they may be subjected to medical treatment carried out in what a substitute decision-maker perceives to be their "best interests", which may not conform to their previous wishes that were reached autonomously. In order to preserve autonomy in the anticipation of a lack of capacity, individuals can formalise their health care plans in documents known as advance care directives. In many common law jurisdictions, the use of these types of documents is provided for by legislation. In this thesis I aim to review the legality of these directives where there is no legislation providing for their use, using Ireland as a case study, as the statutory law in Ireland is currently silent on this issue.

I propose that the principle of autonomy which is protected under Irish law allows for the use of advance care directives without the need for legislation. I set out the criteria, as I see them, of a lawful advance care directive under Irish legal jurisdiction. I will address this issue by reviewing the Irish law in relation to the right to autonomy, the criteria for assessment of capacity, and health care decision-making, drawing on relevant examples from other common law jurisdictions.

*Résumé*

Le principe d'autonomie permet à chacun de prendre les décisions relatives à son corps, et par conséquent, permet à l'individu de décider quel traitement médical accepter ou refuser. Toutefois, lorsque l'individu n'a pas la capacité de décider, il ou elle peut être soumis à des traitements médicaux qu'un décideur substitut considère être en son « meilleur intérêt ». Cette décision n'est pas nécessairement conforme aux désirs exprimés par la personne traitée alors qu'elle en avait la capacité. Pour préserver leur autonomie alors qu'ils en ont encore la capacité, certains rédigent un document appelé directive préalable de traitement. Dans plusieurs juridictions de « common law », ces directives font l'objet d'un cadre législatif. Cette thèse considère la légalité de telles directives dans

les juridictions dépourvues d'un tel cadre législatif et utilise l'Irlande comme étude de cas parce que le droit statutaire irlandais ne se prononce pas sur les directives préalables de traitement.

Je suggère que le principe d'autonomie, protégé en vertu du droit irlandais, permet l'usage de directives préalables de traitement en l'absence de législation. Je décris les paramètres, tels que je les perçois, pour l'usage de telles directives en vertu du droit irlandais. Je discute cette question en me penchant sur le doit irlandais en matière d'autonomie, les critères d'évaluation de la capacité, et la prise de décisions de santé, et en m'inspirant d'exemples d'autres juridictions de « common law ».

**Advance Care Directives and Medical Treatment Decision-Making: Preserving Patient Autonomy**

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## Chapter 1: Introduction

In this thesis I will address the preservation of a person's autonomy in the context of medical treatment decision-making, using Irish law as a case study. It is established law that a person's autonomously made health care decisions should be respected. As, Ronald Dworkin said:

> "It is generally agreed that adult citizens of normal competence have a right to autonomy, that is, a right to make important decisions defining their own lives for themselves."[1]

The law is not so clear where a person's ability or capacity to make decisions is in question. Furthermore the refusal of medical treatment may itself call into question an individual's capacity to make that decision and may result in a finding of incapacity. A designation of incapacity has enormous practical, legal and psychological significance for the individual concerned, as explained by law lecturer, Mary Donnelly:

> "Following the designation, she loses the freedom to make decisions for herself, at least in relation to the matter(s) to which the incapacity relates. Instead, others will decide for her on the basis of what they believe to be in her best interests. Depending on the circumstances, she may be told where to live, what medical treatment to have, what contracts she may enter, whether she may bequeath her property and whether or not she may marry or have a sexual relationship. Thus, her fundamental rights to liberty, to autonomy and to privacy will be significantly undermined by the designation of incapacity."[2]

In most common law jurisdictions, it is usually the case that where there are no previously expressed wishes (and where there is no provision for substitute decisions makers, where the substitute decision maker will try to "stand in the shoes" of the

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[1] Ronald Dworkin, *Life's Dominion: An Argument about Abortion, Euthanasia and Individual Freedom* (Alfred A Knopf; New York, 1993) [Dworkin] at 222.

[2] Mary Donnelly, "Assessing Legal Capacity: Process and the Operation of the Functional Test" (2007) 2 Judicial Studies Institute Journal 141, at 142.

incapacitated person and make the decision they would have made), care of the incapacitated person will be decided on the basis of their best interests.[3] The best interest test usually aligns with the preservation of life.[4] In relation to this hierarchy, the Court of Appeal in the United Kingdom has stated:

> "In a case like this there are three tests that have to be applied. First, is the patient capable of taking an informed decision for herself...The next question when what is being proposed amounts to a trespass is whether there is a clear exposition of the patient's wishes before she became incapable, which is capable in law of amounting to a direction as to how she wishes to be treated when no longer capable of taking decisions for herself. The logic behind this is that the important principle of personal autonomy means that each one of us, certainly when we become an adult, is capable of saying no to any infringement of our bodily integrity"[5]

Where neither of the first two tests apply, the Court continued to find that in such circumstances "(o)ne is then left with stage three, which is where the patient's best interests lie."[6] It may be the case that an individual's medical treatment wishes and their "best interests" are divergent.[7] In this thesis, I address the principle of autonomy in the context of medical treatment and how this principle can be preserved in anticipation of diminished capacity through the formalising of a patient's wishes in a document called an advance care directive (ACD). An ACD is defined by the Irish Council of Bioethics as a "statement made by a competent adult relating to the type and extent of medical treatments she or he would or would not want to undergo in the future should he/she be

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[3] *In re F (Mental Patient: Sterilisation)* [1990] 2 AC 1.

[4] See for example, *Fitzpatrick v FK* [2009] 2 IR 7.

[5] *W Healthcare NHS Trust v H* [2005] 1 WLR 834 at 838.

[6] *Ibid* at 840.

[7] For example, cases where persons refuse blood transfusions on the grounds of religious beliefs.

unable to express consent or dissent at that time".[8] In this thesis, I propose that a validly made ACD has the same legal weight as a contemporaneously made medical decision.

I have chosen Ireland as a case study as there is currently no explicit Irish law in relation to the use of ACDs. Therefore the purported use of ACDs is based on common law rights, in particular the right to autonomy, which is a constitutionally protected right under Irish law. There is very little debate in Ireland opposing the use of ACDs but there is no uniform approach, from a health care and/or legal perspective, in relation to the use of ACDs. There also does not appear to be any clear ground in Irish law to allow for surrogate decision-making based on the previously expressed wishes.[9] There are also currently no provisions in Irish law to allow for supported decision-making.[10] This is a topical area of interest in Ireland, with government committees having recently been established to discuss end of life care, including advanced care planning.[11] Furthermore, Irish law in relation to capacity is currently undergoing legislative changes which are open to interpretation in relation to their application and which I will discuss in this thesis.

The Irish Law Reform Commission has recommended that legislation be introduced to provide for the use of ACDs.[12] I intend to question the necessity of legislative intervention in this area. I will be approaching this issue from the argument that legislation is not required in order to make a valid ACD under Irish law and that in fact, the principle of autonomy requires that such a document be respected, once it is a validly made ACD. As stated by Beauchamp and Childress (whose approach to autonomy I will be applying in this thesis):

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[8] Ireland, Irish Council for Bioethics, *Is It Time for Advanced Healthcare Directives?* (Dublin: Irish Council for Bioethics, 2007) [Irish Council for Bioethics, *Advanced Healthcare Directives*] at 1.

[9] Some jurisdictions, such as Ontario, have a statutory hierarchy designating who will serve as substitute decision-maker. See Health Care Consent Act, 1996, SO 1996, c 2, Sch A.

[10] Although this is to be addressed in the Assisted Decision Making (Capacity) Bill 2013, which I will discuss in chapter 5.

[11] Houses of the Oireachtas, "Health Care Committee to Begin Hearings on End of Life Care", see online www.oireachtas.ie/parliament/mediazone/pressreleases/name-18605-en.html.

[12] Ireland, Law Reform Commission, Bioethics: Advance Care Directives (Dublin: Law Reform Commission, 2009) [LRC, *Advance Care Directives*].

> "To respect autonomous agents is to acknowledge their right to hold views, to make choices, and to take actions based on their personal values and beliefs... Respect in this account, involves acknowledging the value and decision-making rights of persons and enabling them to act autonomously."[13]

It is my opinion that an appropriately made ACD would withstand legal scrutiny without the need for legislation. I will argue that Irish precedent on discontinuation of life-sustaining treatment[14] and precedent in relation to the refusal of medical treatment[15] already provide guidelines on the use of ACDs under Irish law. I will address these issues in Chapters Two and Four.

In Chapter Three, I will set out my understanding of the principle of autonomy which I will apply as a working principle in relation to the lawfulness of an ACD. Modern-day interaction of health and law has seen a shift from beneficent paternalism to a prioritisation of autonomy. The exercise of autonomy in relation to medical treatment is an issue fraught with ethical and legal concerns. I embarked on this thesis with the intention of a substantive examination of the ethical issues surrounding the use of ACDs. However, these issues are so numerous and without resolution that I am resigned to reliance on the law. My thesis does not cover what ethically "ought" to be done, but what "can and should" be done as the law currently stands in Ireland. The use of ACDs raises a multitude of ethical concerns and suppositions, which are both fascinating and distracting in equal measure. In the end, I came to the conclusion that I was not in a position to comment on the ethics of ACDs and that I could neither encourage nor discourage their use by individuals on an ethical basis. However, my thesis cannot be a completely exclusionary exercise *vis-à-vis* ethics, as it is based on a judgement that the use of ACDs does not *prima facie* offend any ethical principles (and even this, being a principalistic approach, is itself one method of many for addressing the ethical precept of an ACD).[16]

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[13] Tom L Beauchamp & James F Childress, *Principles of Biomedical Ethics*, 6th ed (New York NY: Oxford University Press, 2009) [Beauchamp & Childress] at 103.

[14] *In Re Ward of Court* [1996] 2 IR 79.

[15] *Fitzpatrick v FK*, *supra* note 4.

[16] I discuss the theory of Principlism in Chapter Two at page 33.

Some of the ethical concerns that will not be addressed in this thesis include, for example, the concept of "response shift"[17], or the burden on a substituted decision maker named in an ACD[18]. I do not believe a strictly legal solution is available to this kind of problem. However, it is fairly categorical that legal clarity is key in the exercise of any right, so for those seeking to preserve their autonomy through the use of ACDs (and for those faced with the implementation of such formalised wishes), I intend to shed clarity on the law in Ireland in relation to their use.

Patients in Ireland are already using certain forms of ACDs. An Irish study conducted in 2003 found that 27% of physicians had experience of ACDs made by Irish patients.[19] Nonetheless, a recurring problem in Ireland is the absence of evidence on medical files as to whether such ACDs were correctly made, which clearly affects their validity.[20] Thus clarity of a legally constituted ACD is indeed necessary.

In my opinion, an Irish court would uphold an ACD, based fundamentally on how the principle of autonomy has been (and should be) applied. In a lecture given in 1986 in relation to life-sustaining treatment, former Judge of the Irish High Court, Judge Declan Costello wrote as follows:

> "...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 deathcare, generally speaking...[I]n the case of the terminally ill, it is very difficult to see what circumstances would justify the

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[17] "Response shift" is the noted situation whereby individuals will often inaccurately predict their future wellbeing given different possible future health states. See Schwartz CE et al, "Response shift theory: important implications for measuring quality of life in people with disability" (2007) 88:4 Archives of Physical Medicine and Rehabilitation 529.

[18] A systematic review of 40 studies representing 2800 substitute decision-makers concluded that making treatment decisions has a substantial negative emotional effect on at least one third of the substitute decision makers. See David Wendler D & Annette Rid, "Systematic review: the effect on surrogates of making substitute treatment decisions for others" (2011) 154:5 Ann Intern Med 336.

[19] Michael N Butler *et al*, "Dissatisfaction with Do Not Attempt Resuscitation Orders: A Nationwide Study of Irish Consultant Physician Practices" (2006) 99(7) Irish Medical Journal 208.

[20] Aoife Barry, "Age Action: Legal clarity needed on Do Not Resuscitate Orders" thejournal.ie, see online www.thejournal.ie/mulross-nursing-home-dnr-768329-Jan2013/.

interference with a decision by a competent adult of the right to forego or discontinue life-saving treatment."[21]

There is the distinct possibility that legislation would unnecessarily encroach upon the right to autonomy by setting out a formal (mandatory) framework to the making of ACDs, which may be more restrictive than currently applicable jurisprudence. There are already limits to the exercise of autonomy under Irish law and I will set out those limits as they would apply to use of ACDs. Those limits currently appear to be as follows:

a) The making of an ACD is limited to those who have requisite capacity to make such a decision. The capacity to make an ACD is based on principles already set out in precedent on refusal of treatment where the person is otherwise competent and where there is a more permanent interference with competency, the guidance is set out as per the Irish law in relation to mental health, being the Irish Mental Health Act[22] and the proposed legislation in relation to capacity;[23] and

b) ACDs can only be used for treatment that is lawful. For example, an ACD would not be valid if it proposed action that would amount to assisted suicide or euthanasia under Irish law.[24] The very recent Irish Supreme Court case of *Fleming v Ireland* has clarified that assisted suicide is unlawful under Irish law.[25]

I address the criteria of a lawful ACD in Chapter Five, "A Lawful Advance Care Directive". The issue of capacity and mental health is extremely fraught and is regularly litigated in Irish courts. For the purposes of this thesis, I will not be focussing on patients who come under the umbrella of mental health or capacity legislation at the time of drafting an ACD;[26]for example, the cases of persons diagnosed as schizophrenics whose

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[21] Declan Costello, "The Terminally Ill-The Law's Concern" (1986) 21 Irish Jurist 35.

[22] Ireland, Mental Health Act 2001.

[23] Ireland, Assisted Decision-Making (Capacity) Bill 2013. I will address this proposed legislation in chapter 5.

[24] Section 2 (2) of the Criminal Law (Suicide) Act 1993.

[25] *Fleming v Ireland* [2013] IEHC 2 [*Fleming v Ireland* (High Court)]; *Fleming v Ireland & ors* [2013] IESC 19 [*Fleming v Ireland* (Supreme Court)].

[26] It appears that these cases will come under the provisions of the new Assisted Decision-Making (Capacity) Bill 2013, which I will discuss in Chapter Five.

competency levels fluctuate but who, once they fall under certain mental health legislative categories, lose the potential to be evaluated as a "competent" person.[27] I will consider the limitations imposed by mental health legislation on the evaluation of capacity and autonomy for the purposes of the making of an ACD, but I will not address the specific application of an ACD to refusal of medical treatment directed at "improving" the conditions that fall under mental health legislation.

This is an area of law that is in need of clarity in Ireland. I hope that this thesis will assist in the provision of solutions to the lacunae that are currently present and that it will allow individuals, who wish to set out an autonomous plan in relation to medical treatment, to do so more confidently. As Søren Kierkegaard is reported to have said: "Life can only be understood backwards; but it must be lived forwards."[28]

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[27] Advance health care directives in such cases are sometimes referred to as "Ulysses" contracts, named after the persona in Greek mythology. It is legally and ethically trickier territory without greater insight into the nature of the condition affecting the person's autonomy.

[28] See online <http://en.wikiquote.org/wiki/Søren_Kierkegaard>.

## Chapter 2: Personal Rights under Irish Law

### 2.1 The Constitutional Rights

Decision-making in relation to medical care and the formalisation, in advance, of the individual's wished for health care treatment(s), implicates various key rights, including the rights to life, to self-determination,[29] to bodily integrity and to privacy. For the purpose of this thesis, I will argue that the use of ACDs under Irish law is best approached as an exercise of the right to *autonomy*, as a facet of the right to life. The relevance of focusing on a particular right relates to how the rights have been interpreted by the Irish courts; where it is possible to form a ranking of rights, the right to life prevails.

The provisions of the Irish Constitution[30] expressly protect the "personal rights" of Irish citizens and the nature and extent of such rights have been broadly interpreted by the Irish courts. These rights are protected under Article 40.3 of the Irish Constitution, which reads:

> "1. The State guarantees in its laws to respect, and, as far as practicable, by its laws to defend and vindicate the personal rights of the citizen.
>
> 2. The State shall, in particular, by its laws protect as best it may from unjust attack and, in the case of injustice done, vindicate the life, person, good name, and property rights of every citizen."

The Courts have interpreted this express provision to include a number of unenumerated rights, including the right to autonomy.

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[29] For the purpose of this thesis, I do not draw a distinction between the phrases "autonomy" and "self-determination" as these phrases are used interchangeably in the Irish jurisprudence. However, the distinction has been made by commentators. See for example Margaret Somerville, "Labels versus Contents: Variance between Philosophy, Psychiatry and Law in Concepts Governing Decision-Making", (1993) 39 McGill L J 179.

[30] The Constitution of Ireland, Bunreacht na hÉireann, was enacted on 1st July 1937.

### 2.1.1 The Right to Life

The right to life is one of the most fundamental rights in Irish law and is guaranteed under Article 40.3.2 of the Constitution. The Irish courts have recognised that the right to life emanates from the right of every individual to life and that the right to life would take precedence where there are interacting or conflicting rights.[31] In the Irish Supreme Court decision of *G v An Bord Uchtala*, Walsh J stated:

> "The right to life necessarily implies the right to be born, the right to preserve and defend (and to have preserved and defended) that life and the right to maintain that life at a proper human standard in matters of food, clothing and habitation."[32]

Frequently in Irish jurisprudence, the right to life is used interchangeably with the concept of the sanctity of life, that is, that life has an intrinsic value. For example, in *In Re a Ward of Court*, Hamilton CJ stated that "The sanctity of human life is recognised in all civilised jurisdictions and is based on the nature of man."[33]

Article 40.3 imposes a strong presumption on preserving life except in exceptional circumstances. This protection of life under the Irish Constitution does not mean that "life must be preserved at all costs" [34] and this right has been interpreted to provide for allowing the natural end to life to take place (as I will discuss further on in this Chapter).

### 2.1.2 The "Natural Rights" to Autonomy, Bodily Integrity, and Privacy

The Irish courts have interpreted Article 40.3 to provide for a series of unenumerated rights which exist as natural rights without requiring express protection in positive law. The existence of these rights stems from the nature of the State as reflected in the

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[31] *In Re a Ward of Court*, *supra* note 14 at 123. In *Attorney General v X* [1992] 1 IR 1 at 57, Finlay CJ observed that there may be instances where it is necessary to prioritise constitutional rights, and when the interaction of such rights is not capable of being harmonised, then a right to life would take precedence over any other right.

[32] *G v An Bord Uchtala* [1980] IR 32 at 69.

[33] *In Re a Ward of Court*, *supra* note 14 at 123.

[34] See *In Re a Ward of Court, supra* note 14 at 161, Denham J stated that "A view that life must be preserved at all costs does not sanctify life."

wording of the Irish Constitution. In the Supreme Court case of *Norris v Attorney General* [35], Henchy J stated:

> "Having regard to the purposive Christian ethos of the Constitution, particularly as set out in the preamble ('to promote the common good, with due observance of Prudence, Justice and Charity, so that the dignity and freedom of the individual may be assured, true social order attained, the unity of our country restored, and concord established with other nations'), to the denomination of the State as 'sovereign, independent, democratic' in Article 5, and to the recognition, expressly or by necessary implication, of particular personal rights, such recognition being frequently hedged in by overriding requirements such as 'public order and morality' or 'the authority of the State' or 'the exigencies of the common good', there is necessarily given to the citizen, within the required social, political and moral framework, such a range of personal freedoms or immunities as are necessary to ensure his dignity and freedom as an individual in the type of society envisaged. The essence of those rights is that they inhere in the individual personality of the citizen in his capacity as a vital human component of the social, political and moral order posited by the Constitution."[36]

For the purposes of the consent to or refusal of medical treatment, the most significant unenumerated rights are the rights to autonomy, bodily integrity and privacy. These rights "spring" from the natural right to life.[37] I propose that, of these rights, autonomy is the most important with respect to the use of ACDs.

In the High Court decision of *In Re a Ward of Court*, Lynch J noted that the provision in Article 40.3 "reserves to the citizen within the limits required by the common good and public order and morality, autonomy over his own life." [38] The right to autonomy has been found to be based on the right to life. In *In Re a Ward of Court* ,the Supreme Court,

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[35] *Norris v Attorney General* [1984] IR 36.
[36] *Norris v Attorney General*, *supra* note 35 at 72.
[37] *G v An Bord Uchtála*, *supra* note 32 at 69.
[38] *In Re a Ward of Court*, *supra* note 14 at 94.

per Denham J[39] stated the respect for autonomy is based on the right to life, under Article 40.3.2, and that "(i)n the recognition of autonomy, life is respected".[40]

This approach was followed in the recent decision of the High Court in relation to assisted suicide, *Fleming v Ireland*, where Kearns P noted:

> "At the heart of the plaintiff's case is her contention that inasmuch as Article 40.3.2 of the Constitution protects her "person", this also necessarily embraces decisions concerning her personal welfare, including medical treatment. It is, of course, perfectly clear that the protection of personal autonomy in matters of this kind is a core constitutional value." [41]

No definition has been given to "autonomy" in the relevant Irish jurisprudence; however, the application of the right appears to amount to the right to control over how one lives. In this jurisprudence, autonomy is sometimes referred to as the right to self-determination. For example in *In Re a Ward of Court*, Hamilton CJ stated:

> "[Natural rights] include the right to live life in its fullest content, to enjoy the support and comfort of her family, to social contact with her peers, to education, to the practice of her religion, to work, to marry and have children, to privacy, to bodily integrity and to self-determination."[42]

In Chapter Three, I endeavour to offer an understanding of "autonomy" that would be supported by Irish law.

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[39] As she then was, she is now Denham CJ.

[40] *In Re a Ward of Court*, *supra* note 14 at 160. Similarly in the decision of the Ontario Court of appeal in *Malette v Shulman* 67 DLR (4th) 321, Robins JA recognised that "individual free choice and self-determination are themselves fundamental constituents of life. To deny individual freedom of choice, with respect to their health care, can only lessen and not enhance the value of life."

[41] *Fleming v Ireland* (High Court), *supra* note 25 at paragraph 49

[42] *In Re a Ward of Court*, *supra* note 14 at 124.

The right to bodily integrity is another unenumerated right protected by Article 40.3. It is likewise recognised by the Irish courts in the case of *Ryan v Attorney General* [43], where Kenny J stated as follows:

> "In my opinion, one of the personal rights of the citizen protected by the general guarantee is the right to bodily integrity. I understand the right to bodily integrity to mean that no mutilation of the body or any of its members may be carried out on any citizen under authority of the law except for the good of the whole body and that no process which is or may, as a matter of probability, be dangerous or harmful to the life or health of the citizens or any of them may be imposed (in the sense of being made compulsory) by an Act of the Oireachtas. This conclusion, that there is a right of bodily integrity, gets support from a passage in the Encyclical Letter, "Peace on Earth": 'Beginning our discussion of the rights of man, we see that every man has the right to life, to bodily integrity and to the means which are necessary and suitable for the proper development of life; these are primarily food, clothing, shelter, rest, medical care, and finally the necessary social services.'"[44]

Under Irish law, the requirement for consent to medical treatment appears to be based in respect for the right to bodily integrity. In *In re a Ward of Court*, the Supreme Court found that the use of artificial nourishment constituted an interference with the bodily integrity of the patient concerned.[45] In *MX (APUM) v Health Service Executive & ors*, the applicant argued, and the High Court agreed, that the right to bodily integrity, being a distinct right from the right to autonomy, provides protection from unnecessary physical invasive treatment.[46]

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[43] *Ryan v Attorney General* [1965] IR 294.
[44] *Ryan v Attorney General*, *supra* note 43 at 313.
[45] *In Re a Ward of Court*, *supra* note 14 at 125.
[46] *MX (APUM) v Health Service Executive & ors* [2012] IEHC 491 at paragraphs 1 and 49.

Decision-making in relation to medical treatment also invokes the right to privacy, an unenumerated right under Article 40.3.[47] In the case of Norris *v The Attorney General*, Henchy J addressed the nature of the right to privacy as follows:

> "There are many other aspects of the right of privacy, some yet to be given judicial recognition. It is unnecessary for the purpose of this case to explore them. It is sufficient to say that they would all appear to fall within a secluded area of activity or non-activity which may be claimed as necessary for the expression of an individual personality, for purposes not always necessarily moral or commendable, but meriting recognition in circumstances which do not engender considerations such as State security, public order or morality, or other essential components of the common good."

The right to privacy, under Irish law, appears to have the nature of a negative right, concerning areas of personal life that are protected from State interference. Part of the right to privacy is the legal requirement for giving or refusing of consent to medical treatment, as recognised by the Supreme Court *In Re a Ward of Court,* with the right to privacy growing "as the degree of bodily invasion increases".[48] The Irish courts have found that a person does not lose the right to privacy because they lack capacity. In *In Re a Ward of Court* Denham J noted:

> "Merely because medical treatment becomes necessary to sustain life does not mean that the right to privacy is lost, neither is the right lost by a person becoming insentient. Nor is the right lost if a person becomes insentient and needs medical treatment to sustain life and is cared for by people who can and wish to continue taking care of the person."[49]

The unenumerated rights which I have addressed in this section are not unqualified and may be limited in accordance with the requirements of the common good; they are also

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[47] *McGee v Attorney General* [1974] IR 284.
[48] *In re Quinlan* (1976) 355 A 2d 647, as referred to in *In Re a Ward of Court*, *supra* note 14 at 163.
[49] *In Re a Ward of Court*, *supra* note 14 at 163.

subject to the vindication of the rights of others.[50] This qualification was recently recognised by the Irish High Court in *Fitzpatrick v FK*, where Laffoy J stated:

> "(T)he absoluteness of the recognised right to decline medical treatment may be watered down by a competing constitutional interest, whether the concept of the common good or the constitutionally-protected right of a third party, of sufficient weight to override the right".[51]

The limitation of these rights will be addressed in the following chapters of this thesis.

## 2.2 The Application of These Rights to Medical Treatment: the Case of *In Re a Ward of Court*[52]

The application of these rights to the issue of medical treatment was, most famously, addressed by the Irish courts the case of *In Re a Ward of Court*.[53] In this case, the Court looked at whether the right to life extended to a right to die a natural death.

This case concerned a woman in her 40s who had been made a Ward of Court subsequent to suffering serious irreversible brain damage; in the Irish ward of court system, a person who lacks capacity to manage their own affairs is taken under the care of the courts.[54] The condition of the Ward was described as a near permanent vegetative state ("PVS").[55] The Ward's heart and lungs were functioning normally however she required assistance with nutrition and hydration. She also had no capacity for speech or communication.

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[50] In *Kennedy v Ireland* [1987] 1 IR 587, at 592, Hamilton P stated as follows in relation to the qualification of the right to privacy: "It is not an unqualified right. Its exercise may be restricted by the constitutional rights of others or by the requirements of the common good and is subject to the requirements of public order and morality,

[51] *Fitzpatrick v FK*, *supra* note 4at 19.

[52] *In Re a Ward of Court*, *supra* note 14.

[53] *Ibid*.

[54] I discuss the ward of court system in chapter 5 at section 5.1.2

[55] There is no substantive legal definition of such PVS, however the Supreme Court, per Denham J, adopted the definition of PVS as set out in *Airedale NHS Trust v Bland* [1993] AC 789. A detailed description of the condition of the Ward is set out in decisions of the Courts. See *In Re a Ward of Court*, *supra* note 14.

With no prospect of improvement or recovery, the family of the Ward applied to the High Court for an order to discontinue all "artificial nutrition and hydration" and to allow for the "non-treatment of infections or other pathological conditions" which may have affected the Ward (save in a palliative way).[56] The taking of these measures would have surely resulted in the death of the Ward in a short space of time; therefore, they concerned her right to life. The Court was asked to address the question of whether this course of action was lawful.[57]

As the Ward was incapable of making her own decisions, the Court acted pursuant to its *parens patriae* jurisdiction. This is a jurisdiction inherent in the courts in Ireland that is exercised in relation to those who lack capacity to make their own decisions.[58] Under this jurisdiction, the Court is empowered to decide on matters on the basis of the "best interests" of the incapacity person. In deciding on the best interests of the Ward, the High Court per Lynch J held that "(t)he Court should approach the matter from the standpoint of a prudent, good and loving parent in deciding what course should be adopted."[59] The Court was obviously aided in this analysis by the evidence given to the Court by the actual "prudent, good and loving" mother of the Ward; such evidence which was that the Ward, in her current condition, would not wish for the life supporting treatment to continue.[60] There was no evidence of any previously expressed healthcare wishes of the Ward, but the High Court found that it was highly probable (based on the evidence put forward by the Ward's family) that the Ward would choose not to continue to live in her condition.[61]

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[56] *In Re a Ward of Court*, *supra* note 14 at 84.

[57] Although there was theological and ethical evidence put before the High Court, Lynch J expressly stated that, while this evidence was helpful, the Court was not deciding on the moral correctness but the legality of the order to discontinue nutrition and hydration. See *In Re a Ward of Court*, *supra* note 14 at 90.

[58] See for example, the case of *In Re J a Minor (wardship; Medical Treatment)* [1991] Fam 33,where, at 50, the English Court of Appeal stated: "In deciding in any given case what is in the best interests of the ward, the court adopts the same attitude as a responsible parent would do in the case of his or her own child; the court, exercising the duties of the Sovereign as *parens patriae* is not expected to adopt any higher or different standard than that which, viewed objectively, a reasonable and responsible parent would do."

[59] *In Re a Ward of Court*, *supra* note 14 at 99.

[60] *Ibid*.

[61] *Ibid*.

The High Court came to the conclusion that it was in the best interests of the Ward that the artificial nourishment be terminated thus allowing her to die "in accordance with nature and with all such palliative care and medication" so as to ensure a peaceful and pain-free death."[62] The Court also authorised the non-treatment of any infection or condition, save in a palliative way to avoid pain and suffering.

In reaching its conclusion, the High Court adopted the approach of Goff LJ in the decision of the House of Lords in *Airedale NHS Trust v Bland*, who when faced with issues relating to the withdrawal of treatment stated:

> "(T)he question is not whether the doctor should take a course which will kill his patient, or even take a course which has the effect of accelerating his death. The questions is whether the doctor should or should not continue to provide his patient with medical treatment or care, which, if continued, will prolong his patient's life... the question is not whether it is in the best interests of the patient that he should die. The question is whether it is in the best interests of the patient that his life should be prolonged by the continuance of this form of medical treatment or care."[63]

The decision of the High Court was appealed by the Attorney General on the grounds that the decision failed to vindicate the life of the Ward in accordance with Article 40.3. The Supreme Court held that the nature of the right to life, and its importance, imposed a strong presumption in favour of taking all steps capable of preserving it, save in exceptional circumstances.[64] The Supreme Court upheld the decision of the lower court, finding that the right to life as protected under Article 40.3 included the right to die a natural death and the right not to have life artificially maintained.[65] In relation to this right, Hamilton CJ stated:

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[62] *In Re a Ward of Court*, *supra* note 14 at 99.
[63] *Airedale NHS Trust v Bland* [1993] AC 789 at 868.
[64] *In Re a Ward of Court*, *supra* note 14 at 123.
[65] *Ibid* at 124.

> "As the process of dying is part, and an ultimate, inevitable consequence, of life, the right to life necessarily implies the right to have nature take its course and to die a natural death and, unless the individual concerned so wishes, not to have life artificially maintained by the provision of nourishment by abnormal artificial means, which have no curative effect and which is intended merely to prolong life."[66]

The Supreme Court, per Blaney J, held that the High Court had complied with the constitutional obligation to vindicate the Ward's right to life "by addressing very fully the question of whether or not it was of any benefit to the ward to prolong her life given the burdens on the ward involved in doing so and the fact that no improvement in the ward's condition can be expected."[67]

The Court stressed, albeit in *obiter*, that a competent person if terminally ill has the right to forego lifesaving treatment. As the Court considered the Ward to be "terminally ill", the Court was satisfied that if the Ward were mentally competent, she would have in the circumstances of her condition, the right to forego or to the withdrawal of life sustaining treatment.[68] The Court also found that, on the circumstances of the case, there was no requirement to limit the Ward's constitutional rights in the interests of the common good or public morality.[69]

In his decision in the case, Hamilton CJ considered the Ward to be terminally ill based on the evidence that she would certainly die within a short period of time if artificial nourishment were removed. This is a very broad interpretation of "terminally ill". I do not think that it is too flippant to say that Hamilton CJ's interpretation of "terminally ill" would mean that most individuals are constantly in a terminal state as few would survive

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[66] *In Re a Ward of Court*, *supra* note 14 at 124.

[67] *Ibid* at 143; In his dissenting judgment in *In Re a Ward of Court,* supra note 14 at 137, Egan J found that it would not be lawful to remove the artificial nourishment as it would result in death.

[68] *Ibid* at 126.

[69] *Ibid*.

the removal of nourishment.[70] In his dissenting opinion, Egan J disagreed with this interpretation of "terminally ill" in his decision in the matter, based on the possibility that the Ward may have lived with artificial nourishment.[71] There may be little relevance to this distinction, as I do not believe that current Irish law limits the right to refuse treatment to those who are terminally ill.[72]

The Supreme Court unfortunately could not enter into any lengthy examination of the wishes of the Ward. The Supreme Court acknowledged that there was in fact very little or no useful evidence in relation to what would have been the wishes of the Ward.[73] As there was no such evidence, the Court relied on the "best interests" of the Ward. This is disappointing, following any reasonable examination of the principle of autonomy. However, it could be debated that the mere consideration by the Court of existence of such evidence leans towards an obligation to take such evidence into consideration.

Most of the findings made by the Supreme Court that are relevant to this thesis, were made in *obiter*, as they did not apply to the particular facts of the Ward. Importantly, the Supreme Court clearly set out that the competent person has a right to forego treatment, stating:

> "There is no doubt but that the ward [the patient concerned in the case], if she were mentally competent, had the right, if she so wished, to forego such treatment

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[70] I believe that a better approach to this point was followed in the High Court decision in this case, *In Re a Ward of Court*, *supra* note 14 at 95, where Lynch J stated: "A distinction was drawn in the medical evidence between a patient who is terminally ill on the one hand and a patient who has an incurable disease on the other hand. A person is terminally ill who is suffering from a progressive disease which will result in his death within a matter of months and probably at the very outside, not more than six months. A person who has an incurable disease will suffer from that disease for the rest of his life but it will not get any worse or else it will progress and get worse so gradually that he may, despite the disease, live for many more years. The ward is not suffering from a terminal disease in the foregoing sense of a progressive condition, although I think that there is some substance in what one of the doctors said, namely, "she would be terminally ill if not falsely maintained: it is horrendous". The ward's condition is static: it will never improve: she will never recover but, as already stated, she could live, assuming nourishment continues to be given to her for another twenty years or so."

[71] *In Re a Ward of Court*, *supra* note 14 at 137.

[72] See *Fitzpatrick v FK*, *supra* note 4.

[73] *In Re a Ward of Court*, *supra* note 14 at 136.

> or, at any time, to direct that it be withdrawn even though such withdrawal would result in her death."[74]

In her judgment in the matter, Denham J noted that consent to medical treatment need not be based on medical considerations and that such treatment may be refused for reasons "other than medical reasons, or reasons most citizens would regard as rational."[75] Furthermore, the Supreme Court, per O'Flaherty J stated, in *obiter*, that Irish law may provide for the concept of substituted decision-making, in the event of incapacity of the patient, where "the person had the foresight to provide for future eventualities."[76]

## 2.3 Does Article 40.3 Include a Right to Die?

In the decision of *In Re a Ward of Court*, the Irish Supreme Court made it clear that the case did not concern the taking of active steps to end life. The Court rejected, in *obiter*, the use of medical treatment to terminate life under Irish law, stating that "even in the case of the most horrendous disability, any course of action or treatment aimed at terminating life or accelerating death is unlawful".[77] The Supreme Court's decision draws an ethical and legal line in the sand between the taking of active steps to end life and the withdrawal of treatment. The Supreme Court viewed the act of removal of the artificial nourishment and withholding of medication, save for palliative care, as allowing "nature to take its course" and was therefore allowable under Irish law as the right to life includes a right to a natural death.[78] Planning for end of life care is encompassed by the Constitutional right to life, as Denham J stated in *In Re a Ward of Court*:

> "A person and / or her family who have a view as to the intrinsic sanctity of life in question are in fact encompassed in the constitutional mandate to protect life for the common good-what is being protected (and not denied, ignored or overruled)

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[74] *In Re a Ward of Court*, *supra* note 14 at 133.
[75] *Ibid* at 156.
[76] *Ibid* at 133.
[77] *Ibid* at 120.
[78] *Ibid* at 130.

> is the sanctity of that person's life. To care for the dying, to love and cherish them, and to free them from suffering rather than simply to postpone death, is to have fundamental respect for the sanctity of life and its end"[79]

Although the use of the word "simply" is regrettable since it is undoubtedly not an easy decision either way, the comments of Denham J highlight the constitutional mandate which provides for the protection of life by not preventing or delaying its end.

However, this right does not include a right to die. Any doubt remaining about the existence of this right has been empathically cast aside by the recent ruling of the Irish Supreme Court in the case of *Fleming v Ireland*. In this decision, the Supreme Court found, in no uncertain terms, that Article 40.3 does not provide for a right to have life terminated.[80] The Court found that the right to life, as provide for in the Irish Constitution, did not extend to the right for an individual to terminate his or her life or to have assistance in so doing.[81] The Supreme Court, per Denham CJ, stated:

> "The right to life which the State is obliged to vindicate, is a right which implies that a citizen is living as a vital human component in the social, political and moral order posited by the Constitution."[82]

The applicant in *Fleming v Ireland* argued that her right to autonomy under Article 40.3 included a right to terminate her life. The Court rejected this argument, stating:

> "The concept of autonomy which extends not just to an entitlement, but to a positive right to terminate life and to have assistance in so doing, would necessarily imply a very extensive area of decision in relation to activity which is put, at least *prima facie*, beyond regulation by the State . When it is considered that recognition of such a right implies correlative duties on the State and others to defend and vindicate that right (and which must necessarily restrict those

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[79] *In Re a Ward of Court*, *supra* note 14 at 161.

[80] *Fleming v Ireland* (Supreme Court), *supra* note 26 at paragraphs 113-114. I will address this decision further in Chapter 5 under section 5.3.1.

[81] *Ibid* at paragraph 113.

[82] *Ibid*.

parties' freedom of action), it is apparent that the right contended for by the appellant would sweep very far indeed. It cannot properly be said that such an extensive right or rights is fundamental to the personal standing of the individual in question in the context of the social order envisaged by the Constitution."[83]

It is therefore clear that the rights provided for by Article 40.3 do not extend to a right to die.

## 2.4 Addressing the Conflation of the Unenumerated Rights by the Irish Courts

Often the Irish courts have conflated the rights to autonomy, bodily integrity and privacy, perhaps to the point where there could be an argument made that there is little material difference in the rights exercised in decision-making in relation medical treatment. Self-determination and bodily integrity are so intertwined by the relevant precedent of the Irish courts that they are almost be interchangeable as ideas and rights. The conflation in the approach of the Irish courts in relation to these rights is clearly seen in the High Court decision of *In Re a Ward of Court*, where Lynch J stated:

> "Thus it has long been accepted that a competent terminally ill patient may elect not to allow or accept treatment which may prolong his life and if incompetent, that the medical carers, in agreement with the patient's family, may adopt the same course. This illustrates that despite the fact that *the right to life ranks first in the hierarchy of personal rights, it may nevertheless be subjected to the citizen's right of autonomy or self-determination or privacy or dignity, call it what you will,* whether exercised by himself, if competent, or on his behalf by agreement between carers and family all acting *bona fide* in the patient's best interests. Indeed, the patient himself being competent, may lawfully decline medical treatment even though not terminally ill which he reasonably considers to be excessively burdensome, having regard to the paucity of benefit to be realised

[83] *Fleming v Ireland* (Supreme Court), *supra* note 26 at paragraph 113.

> thereby and notwithstanding that the absence of such treatment may lead to his death."[84]

There appears to be confusion in Irish legal argument as to the genesis and nature of the rights. Legal counsel in the recent case of *Fitzpatrick v FK* submitted in argument that the right of patient autonomy is a dimension of the unenumerated right to bodily integrity.[85] This approach diverges with previous jurisprudential approaches, which separate the rights to autonomy and bodily integrity.[86]

It is worth noting that the conflation of the right to autonomy or self-determination and the right to bodily integrity is not placed solely at the feet of the Irish courts. In the decision of the Pennsylvanian Supreme Court, *In re Fiori*, which was cited with approval by the Supreme Court in *In Re a Ward of Court*[87], Popovich J conflates bodily integrity and self-determination as follows:

> "Equally applicable to the right of an individual to forego life sustaining medical treatment is the common law right to freedom from unwanted interference with bodily integrity ('self-determination')"[88]

Likewise, in the decision of the Supreme Court of Canada in the case of *Ciarlariello v Schacter*, Cory J stated:

> "It should not be forgotten that every patient has a right to bodily integrity. This encompasses the right to determine what medical procedures will be accepted and the extent to which they will be accepted. Everyone has the right to decide what is to be done to one's own body. This includes the right to be free from medical

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[84] *In Re a Ward of Court*, *supra* note 14 at 94.
[85] As recognised by the Court in *Ryan v Attorney General*, *supra* note 43.
[86] See for example, *In Re a Ward of Court*, *supra* note 14.
[87] *In Re a Ward of Court, supra* note 14 at 132.
[88] *In Re Fiori* (1995*)* 652 AR 2d. 1350.

> treatment to which the individual does not consent. This concept of individual autonomy is fundamental to the common law..."[89]

Why should this conflation matter? It is clear that these rights are separate and distinct.[90] Although sometimes conflated by the Courts, these rights have *inherently* distinct characteristics. These rights also have distinct characteristics as concepts in ethical argument, in particular autonomy. Where there is an intersection with law and ethics, such as decision-making in medical treatment, clarity of terminology is the key to any successful argument.

Logically then, I propose that the use of ACDs should be seen as an exercise of the right to autonomy; autonomy being a part of the right to life. This logic is in line with the reasoning in the judgment of Denham J in *In Re a Ward of Court*, where she similarly states:

> "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 example, refuse a blood transfusion for religious reasons. In the recognition of the individual's autonomy, life is respected."[91]

Approaching autonomy as a legal subset (perhaps, "sub-concept") of the right to life must then endorse, so to speak, the use of ACDs in the strongest possible fashion, particularly

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[89] *Ciarlariello v Schacter*, [1993] 2 SCR 119, at 135.

[90] That these rights are separate and distinct can be seen, *inter alia*, from the statutory provision of Section 4(3) of the Ireland, Mental Health Act 2001, which provides "In making a decision under this Act concerning the care or treatment of a person (including a decision to make an admission order in relation to a person) due regard shall be given to the need to respect the right of the person to dignity, bodily integrity, privacy *and* autonomy."[emphasis added].

[91] *In Re a Ward of Court*, *supra* note 14at 160; This echoes the words of Robins JA in *Malette v Shulman* (1987), 63 OR (2d) 243, 67 DLR (4th) 321, where he stated: "The principle of self determination and individual autonomy compel the conclusion that the patient may reject blood transfusions even if harmful consequence may results and even if the decision is generally regarded as foolhardy."

where the Irish Constitution has clearly interpreted the right to life to take precedence over other conflicting rights[92] in effect rendering this right *a priori*.

There are also potentially limiting aspects to the right to bodily integrity and the right to privacy that do not exist with the right to autonomy. The application of the right to bodily integrity under Irish law is problematic given the relatively narrow, and yet still vague, description of the right set out in the seminal Irish case on this right; that is, *Ryan v AG*.[93] The weakness of this narrow definition was put to Supreme Court in argument during the appeal of the case, but unfortunately the Supreme Court held that it was unnecessary to define "bodily integrity".[94] It is this vague definition of bodily integrity which maintains a foothold in Irish law, particularly in relation to decision-making in medical treatment. In *In Re a Ward of Court*, the Supreme Court, per O'Flaherty J, found that the right to refuse medical treatment was founded on the constitutional rights of bodily integrity and privacy.[95] In her decision in the same matter, Denham J, elaborated on the right to bodily integrity as it interacts with medical treatment as follows:

> "The medical treatment is invasive. This results in a loss of bodily integrity and dignity. It removes control of self and control of bodily functions. When medical treatment is ingested, inhaled or applied then there is a voluntary co-operative effort by the patient and each time a voluntary effort occurs the patient reveals to their carers their continuing consent to treatment which invades the integrity of the body...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.[96]

When bodily integrity is interpreted in this manner it may protect the competent person from unwanted medical treatment, but it does not necessarily provide for the formalisation of health care wishes as envisaged by the typical use of ACDs. Inviolability

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[92] See *In Re a Ward of Court*, *supra* note 14 at 123.
[93] *Ryan v AG*, *supra* note 43.
[94] *Norris v The Attorney General*, *supra* note 35 at 72.
[95] *In Re a Ward of Court*, *supra* note 14at 130.
[96] *Ibid* at 158.

may be a shield against unwanted invasion but it is not a sword that can be used to beat a self-determined path. Of course, bodily integrity ("inviolability") is not the same as autonomy, even if is a facet of autonomy. This was recognised by the Supreme Court of Canada in *Rodriquez v Canada*, where Sopinka J stated:

> "In my view, then, the judgments of this Court in *Morgentaler* can be seen to encompass a notion of personal autonomy involving, at the very least, control over one's bodily integrity free from state interference and freedom from state-imposed psychological and emotional stress...There is no question, then, that personal autonomy, at least with respect to the right to make choices concerning one's own body, control over one's physical and psychological integrity, and basic human dignity are encompassed within security of the person, at least to the extent of freedom from criminal prohibitions which interfere with these."[97]

I believe that the right to privacy is not fully satisfactory in relation to the use of ACDs, despite the interpretation of this right's interaction with the refusal of medical treatment. In *In Re a Ward of Court*, Denham J bases the right to refuse treatment on the right to privacy, as I have referred to above.[98] The difficulty with the right to privacy, as with the other rights, is that it is not absolute and must be balanced with the State's duty to protect and vindicate life.[99] The right to bodily integrity can be transgressed in the case of best interests, where the person is not competent. [100] The right to privacy has been limited by the State in the protection of public morality.[101] The further weakness with the right to privacy, as stated above, is that this right appears to have been interpreted by the Irish courts as a negative right, in that the State cannot, through its laws and actions transgress the right of in an individual to privacy.[102]

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[97] *Rodriguez v British Columbia (Attorney General)* [1993] 3 SCR 519.

[98] *In Re a Ward of Court*, supra note 14 at 163

[99] *Ibid*.

[100] This is seen in the case law on the application of the Ireland, Mental Health Act 2001. I address the point in section 5.1.3.

[101] *Norris v AG*, *supra* note 35.

[102] Margaret Somerville, "Labels versus Contents: Variance between Philosophy, Psychiatry and Law in Concepts Governing Decision-Making", (1993) 39 McGill L J 179 at 190.

Thus my preferred approach to the use of ACDs is as a positive right or freedom, meaning that one should have freedom to act autonomously in relation to medical treatment, within the allowed constitutional limitations.

## 2.5 Conclusions

When there is a proper and clear distinction drawn between the rights to autonomy, bodily integrity and privacy, their different values and applications become clearer; and, more purposeful. It is my argument that it is *autonomy* which is at stake in the making of an ACD, since it is autonomy which most informs any plan for how an individual wants to live (or die). The use of ACDs is best seen as an exercise of autonomy under the right to life.

This is the approach taken in other jurisdictions, such as Canada, where the principle of autonomy provides the underlying rationale for decisions relating to the control of individuals over their medical treatment decisions.[103] In *Malette v Shulman*, the Ontario Court of Appeal stated:

> "The right to determine what shall be done with one's own body is a fundamental right in our society. The concepts inherent in this right are the bedrock upon which the principles of self-determination and individual autonomy are based. Free individual choice in matters affecting this right should, in my opinion, be accorded very high priority."[104]

The Canadian Courts have also held that right to autonomy is fundamental and should prevail over competing rights.[105]

I will address the relevance and value of the principle of autonomy in the following chapter.

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[103] See *Malette v Shulman* (1987), 63 OR (2d) 243, 67 DLR (4th) 321; *Nancy B v Hôtel-Dieu de Québec* (1992), 86 DLR (4th) 385 (Que SC); *Ciarlariello v Schacte*r, *supra* note 89; *Rodriquez v Canada*, *supra* note 97.

[104] *Malette v Shulman* (1987), 63 OR (2d) 243, 67 DLR (4th) 321[cited to DLR] at 336.

[105] *Starson v Swayze*, 2003 SCC 32, [2003] 1 SCR 722.

## Chapter 3: The Value of Autonomy

### 3.1 Introduction

The main argument for ensuring that an individual has a right to choose their medical treatment (to the extent possible taking into consideration resources and means and no other public health concerns) is that as competent human beings, we operate under the principle of autonomy. At this stage, I would like to take a step back from the law in relation to this issue and look more at the philosophical theory which has a bearing on personal choice and medical treatment. I also wish to set out the understanding of autonomy that I am using as the basis for this thesis.

The word autonomy is derived from the Greek for self-rule ("autos" meaning self and "nomos" meaning rule or governance).[106] In the present it seems an entirely automatic response to highly value autonomy, but this has not always been the case, particularly in relation to medical treatment. Historically the physician-patient model was a paternalistic one and the weight place on autonomy over other considerations is a relatively modern approach. [107] The emergence of the pre-eminence of the principle of autonomy in relation to medical treatment is a reaction to this historical patriarchal practice of medicine, in which relatively little weight was placed on patient consent or awareness of treatment. In medicine, it was the case that the principles of non-maleficence and beneficence played a greater role; the principle of beneficence requires practitioners to do what is in the best interests of their patients and non-maleficence requires practitioners to first do no harm and where harm is unavoidable, to do the least amount of harm possible. In his writings on autonomy, Robert M Veatch, the bioethicist, says:

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[106] Tom L Beauchamp & James F Childress, *Principles of Biomedical Ethics*, 6th ed (New York NY: Oxford University Press, 2009) at 99 [Beauchamp & Childress].

[107]Ezekiel J Emmaual & Linda L Emmanual, "Four Models of the Physician-Patient Relationship" (1992) 267:16 JAMA 2221 at 2221.

> "Traditional paternalistic Hippocratic medicine forced us to focus on autonomy... the function of autonomy was to liberate the patient from the oppression of the physician's paternalism."[108]

In an Irish context, the undervaluation of autonomy by the medical profession is seen most starkly in the treatment of women during and after childbirth, such as the cases of symphysiotomy carried out on women following child birth, without the women's knowledge or consent.[109] The possibility that an individual, who is a competent adult, would not have the "final say" in their medical treatment undoubtedly offends the modern sensibility and this is reflected in case law on such matters.[110]

For health care practitioners, autonomy is not merely an ideal but an obligation; autonomous choice being a right and not a duty of patients.[111]

Despite my disclaimer in the introduction that I would not undertake an ethical examination of the issues arising in relation to the use of ACD, I am taking the epistemological path that autonomy is *prima facie* a good thing and should be upheld in relation to medical treatment. This view is reflected by jurisprudence of the Irish Court and, as I have stated, it seems to be the inclination of most ethicists, especially those proponents of the theory of Principlism. Principlism is one of a number of theories that have emerged in the study of ethical issues arising in the context of medical care, or biomedical ethics (bioethics); the theory aims to provide ethical resolution to issues through reflective analysis of four static principles, being autonomy, beneficence, non-maleficence (discussed above), and justice. As with all critical theories, there is ebb and flow over time, and there have been much criticism of the traditional view of autonomy

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[108] Robert M Veatch, "Which Grounds for Overriding Autonomy are Legitimate", (1996) 26:6 Hastings Centre Report, 42 at 42 [Veatch, "Overriding Autonomy"].

[109] Symphysiotomy is a surgical procedure in which the cartilage of the pubic bone is divided to widen the pelvis allowing childbirth. It is a procedure that is currently eschewed in western medical practice. See The Journal, "'Appalling', 'ghastly' and 'brutal' – doctors describe symphysiotomy ordeal", The Journal, www.thejournal.ie/symphysiotomy-survivors-petition-messages-858418-Apr2013/.

[110] *In Re a Ward of Court*, *supra* note 14.

[111] Beauchamp & Childress, *supra* note 106 at 107. While this is a cornerstone of applied bioethics, this thesis does not relate to health care policy or patient's rights *vis à vis* health care practitioners. This thesis is directed to the lawfulness of ACD.

in recent years; with some theorists of the opinion that it does not correctly reflect the reality and that it is too abstract to be applied in practice.[112] Some commentators argue that autonomy should be pushed out of its pole position in favour of other competing interests, for example the "common good".[113]

Notwithstanding the long history of discussion or criticisms of the importance of autonomy in biomedical ethics, there is always room for a return to basic principles in order to strengthen an argument and also to renew the importance that any claim has assumed over time and use.

## 3.2 An Understanding of Autonomy

Despite considerable academic commentary, there is little agreement about the full nature, scope or strength of the principle of autonomy and the understanding of what is meant by autonomy is constantly evolving. [114] However, the essence of autonomy is clear; it is the exercise of free will (to the extent that free will exists) in the pursuit of one's preferred life, or, the "good life".[115] While autonomy was never really seen as an unfettered right, the theory that autonomy is "rational self governance"[116] is no longer seen as a full understanding of the principle; autonomy does not require "rationality".[117]

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[112] Rebecca Kukla, "Conscientious Autonomy; Displacing Decisions in Healthcare" (2005) 35:2 Hastings Centre Report 34, at 34; K Danner Clouser and Bernard Gert refer to the theory critically as the "the mantra of Principlism", see K Danner Clouser & Bernard Gert, " A Critique of Principlism" (1990) 15:2 J Med Phil April 219.

[113] Daniel Callahan, "Can the Moral Commons Survive Autonomy?" (1996) 26:6 Hastings Centre Report, 41, at 41-42.

[114] Beauchamp & Childress, *supra* note 106 at 99.

[115] Kim Atkins, "Autonomy and the Subjective Character of Experience" (2000) 17:1 Journal of Applied Philosophy, 71, at 74.

[116] As in an understanding of autonomy that was espoused by John Stuart Mills who wrote "Over himself, over his own body and mind, the individual is sovereign" in "On Liberty", in *Collected Works of John Stuart Mill*, vol 18 (Toronto: University of Toronto Press, 1977).

[117] In relation to the integrity theory of autonomy, Ronald Dworkin says: " the value of autonomy, on this view, derives from the capacity it protects: the capacity to express ones' own character...It recognises that people often make choices that reflect weakness, indecision, caprice or plain irrationality..." See Dworkin, *supra* note 1 at 224.

Neither is autonomy, especially in biomedical ethics, purely individualistic.[118] It will be the rare human who will come to a decision based "free" from the weight of their experience or their relationships with others. Autonomy still deserves to be respected despite this failure to attain "full" or "perfect" autonomy. More modern theories on autonomy accommodate this reality.

For the purposes of a harmonious non-disjointed approach in this thesis, I will apply Beauchamp and Childress' understanding of autonomy, which has been the preeminent understanding of autonomy in biomedical ethics for nearly 30 years.[119]This understanding of autonomy is, in brief, as follows:

> "Personal autonomy encompasses, at a minimum, self rule that is free from both controlling interference from others and certain limitations such as inadequate understanding that prevents meaningful choice. The autonomous individual acts freely with a self chosen plan."[120]

I will now address the reasons for choosing Beauchamp and Childress' understanding of autonomy as the understanding of autonomy for this thesis, which reasons arise notwithstanding the pre-eminence of the theory in bioethics. Beauchamp and Childress' approach follows the theory of Principlism, which, in my own opinion, is the closest bioethical theory to the traditional common law approach to the resolution of conflicting rules or principles. The "balancing of principles" provides familiar territory to lawyers used to weighing up conflicting rights and obligations; this familiarity allows the theory to be smoothly transposed into a nexus of legal principles in relation to such issues as the use of ACDs.

The theory places fundamental importance on the type of autonomy that Irish law has already recognised.[121] The right to autonomy under Irish law encompasses the right not to

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[118] This position is seen in the traditional Kantian theory of autonomy. See Downie & Macnaughton, *Bioethics and the Humanities, Attitudes and Perceptions*, (Abingdon, Routledge-Cavendish, 2007) at 42.

[119] Beauchamp &Childress' *Principles of Biomedical Ethics* was first published in 1978 and is now in its 6th edition.

[120] Beauchamp & Childress, *supra* note 106 at 99.

[121] See discussion of the right to autonomy under Irish law in Chapter 2.

be treated medically without consenting, in an informed manner, to that treatment. It further encompasses the right to refuse treatment, even in life-threatening situations, in order to give effect to one's own personal beliefs.[122] The understanding of autonomy that has been, and should continue to be, applied by Irish courts (and which is espoused by Beauchamp and Childress), requires intentionality, understanding and the absence of controlling influences.[123]Like the approach taken to date by the Irish courts, this understanding of autonomy is not unlimited and without regard for other considerations, for example, the obligation on health care practitioners to act in the best interests of the patient (or beneficence).[124]

Even though there are similarities between the approach to autonomy in Irish law and that of Beauchamp and Childress, there has been an absence of a defined, clear understanding of autonomy in recent Irish legal discourse on the use of ACDs, such as the Irish Law Reform Commission Report.[125] The decisions of the Irish courts which refer to the right to autonomy have sometimes taken an approach to autonomy that blurs the lines between this principle and others, such as the right to privacy or the right to bodily integrity. Therefore, I believe that a review of the theory may add clarity to the debate and in doing so, add strength to an argument in favour of the protection of the right of a person to make autonomous choices, in partial in the context of medical treatment.

The importance of a defined understanding of autonomy can be better understood when set against the multitude of possible definitions of the principle. For example, some writers maintain that autonomy involves "having the capacity to reflectively control and identify with one's basic (first order) desires or preferences through their higher preferences".[126] My own understanding of autonomy is that it should not require a level of applied philosophy that is extraordinary and not reflected in the reasoning of the

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[122] This is the understanding of autonomy set out in the decision of the Irish Supreme Court in *In Re a Ward*, *supra* note 14.

[123] See *In Re Ward of Court* supra note 14; Beauchamp & Childress, *supra* note 106 at 99.

[124] Beauchamp & Childress, *supra* note 106 at 99.

[125] LRC, Advance Care Directives, *supra* note 12.

[126] See Gerarld Dworkin, *The Theory and Practice of Autonomy*, (New York; Cambridge University Press 1988) Chapters 1-4, as discussed in Beauchamp & Childress, *supra* note 106 at 100.

average person. Autonomy, as a theory, should not be beyond the reach of the average or normal person; this is the understanding of autonomy shared by Beauchamp and Childress, who state that "[n]o theory of autonomy is acceptable if it presents an ideal beyond the reach of normal agents and choosers"[127] The ideal of "full autonomy" where the agent understands completely and fully all possible permutations of a decision and reflects on the same in a perfect rational manner is not workable and is "mythical".[128] For Beauchamp and Childress, a person's appreciation of information in the context of health care must only be "substantially autonomous" and no more than is required, for example, in making financial investments, where the appropriate criteria for this "substantiality" is best addressed in a particular context.[129] This understanding of autonomy also allows for exercise of autonomy by the choosing of an institutional source of direction, such as religious beliefs or medical authority.[130] The relevancy of this is that a person's decision should not be overturned solely on the grounds that it was made in accordance with religious or other values-based system of thought.

An overly individualistic model of autonomy may not be suitable for issue arising in respect of medical treatment because "[m]any of the important, but by no means unusual, health-care decisions that individuals, friends and families make are far removed from the cool reflective clear headed decision making that is the paradigm of this view of autonomy."[131] While the family is an important unit in Irish law, the Irish courts' understanding of autonomy appears to favour the wishes of the individual over those of the community or family[132] and this should be reflective in the understanding of autonomy in the discussion of the use of ACDs. An approach to autonomy that is in accordance with Irish law cannot place too weighty an emphasis on community or relational decision making, to the point of requiring this kind of decision making. The

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[127] Beauchamp & Childress, *supra* note 106 at 101.

[128] *Ibid* at 102.

[129] *Ibid* at 101.

[130] *Ibid* at 102.

[131] Susan Dodds, "Choice and Control in Feminist Bioethics", in Mackenzie & Stoljar (eds) *Relational Autonomy: Feminists Perspectives on Autonomy, Agency and the Social Self,* (New York: Oxford University Press 2000), 213 at 217.

[132] See the Irish Supreme Court decision *In Re a Ward of Court*, *supra* note 14.

Beauchamp and Childress approach requires neither detached decision making nor excludes the importance of relations; this approach is in accordance with Irish law.

This understanding of autonomy, rightly, does not exclude examination of the strength or validity of an autonomous decision. According to Beauchamp and Childress, even a person with full capacity to be autonomous can act in a manner that is not autonomous where there is coercion or other influences or conditions restricting their choices, including temporary constraints on autonomy.[133] Due regard for all potential coercions should be given to the circumstances in which decisions are made. This understanding requires and allows for more than just a cursory evaluation of circumstances of the exercise of autonomy. For example, "an autonomous person who signs a consent form without reading or understanding the form is qualified to act autonomously but fails to do so."[134] Importantly, the person who does this still retains their capacity to be autonomous but has failed to act autonomously. This distinction is vital in relation to the enquiry into the lawfulness of the use of ACD.[135] This understanding of autonomy encompasses the *right* to choose to be informed; and not a mandatory *duty* to be informed.[136]

Further, the approach of Beauchamp and Childress encompasses the choice to delegate decision-making.[137] Clearly, this is an essential part of any approach to autonomy that should be applied in relation to the use of ACDs, which provide for substituted decision making.

### 3.3 Why is it Important to Respect Autonomy?

I have dealt with how autonomy came to the forefront in the issue of medical treatment and set out my working understanding of autonomy. Now I will elaborate on the "why" of respecting or preserving autonomy. Respecting autonomy is recognising that all

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[133] Beauchamp & Childress, *supra* note 106 at 100.
[134] *Ibid* at 101
[135] I will address this point again in Chapter 5 at section 5.2.
[136] Beauchamp & Childress, *supra* note 106 at 105.
[137] *Ibid* at 106

persons have unconditional worth and should have the freedom to determine their own destiny, and that to treat a person otherwise is to treat that person as a "means", without regard to that person's own goals.[138] In its paper on capacity, the Irish Law Reform Commission states that "(t)o be autonomous and capable of self-determination is a large part of what humans cherish in terms of liberty and independence."[139] The preservation and promotion of autonomy is based on the principle that is it an existential good for a person to follow and to develop according to their own convictions; that there is innate worth in this self-direction and freedom as long as it does not harm others.[140]

More contemporary philosophers, such as Ronald Dworkin, who wrote extensively on biomedical issues, also acknowledged that a self-determined life path is an important human good:

> "Recognising an individual right of autonomy makes self-creation possible. It allows each of us to be responsible for shaping our lives according to our coherent or incoherent – but in any case, distinctive – personality. It allows us to lead our lives rather than be led along them, so that each of us can be, to the extent a scheme of rights can make this possible, what we have made of ourselves. We allow someone to choose death over radical amputation or a blood transfusion, if that is his informed wishes, because we acknowledge his right to a life structured by his own values."[141]

Of course, a person's wishes may be disregarded for something that is objectively a "good" thing, for example, a blood transfusion against a person's wishes where it is necessary to save their lives, which would be a quintessential example of beneficence. However, if the understanding of autonomy that I have suggested is applied in such a case, it is less justifiable that someone's meaningfully made choices should be

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[138] See Immanuel Kant, *Foundations of the Metaphysics of Morals*, translated by Lewis White Beck (Indiana: Bobbs Merril 1959) discussed in Beauchamp & Childress, *supra* note 106 at 103.

[139] Ireland, Law Reform Commission, *Report on Vulnerable Adults and the Law: Capacity* (Dublin: Law Reform Commission, 2006) at 20.

[140] See John Stuart Mills, "On Liberty", in *Collected Works of John Stuart Mill*, vol 18 (Toronto: University of Toronto Press, 1977) ( discussed in Beauchamp & Childress, *supra* note 106 at 103).

[141] Dworkin, *supra* note 1 at 224

disregarded without strong competing interests. I would suggest that harm to others is the only case where an autonomously made choice should be disregarded and to do otherwise would not adequately preserve the importance of the principle of autonomy.

In practice, the beneficial effect of protecting and allowing for autonomy can be seen, even where there is lessened capacity, such as in cases of dementia patients where the tradition has been to reduce self-direction. As an example, I would point to the current Danish system for the care of dementia patients which has an underlying philosophy allows every patient, no matter how ill, the right to choose how they live.[142]

On a less specific level, ill health can mean vulnerability for some people, in particular perhaps the biggest fear for some is the unknown, and when it comes to making potentially difficult decisions in relation to health, the exercise of autonomy can liberate individuals from the "tragedy and suffering that vulnerability can mean..."[143]

## 3.4 Conclusions

That there is value in the preservation of autonomy is undeniable and this is most clearly seen in the wrong committed when autonomy has been abused, neglected or denied. In relation to the use of ACD, I suggest the application of an understanding of autonomy which promotes self-determination but promotes also meaningful choice.

Beauchamp and Childress's approach precludes am overly rigorous standard of a "philosopher-level" reflection in relation to personal choices, but also it allows for, while not requiring, physician interaction, in patient decision making, provided this interaction does not amount to coercion. This understanding allows for an examination of the meaningfulness of the putatively autonomous choices made by an individual and a balancing of these choices against other competing, equally important principles, such as justice and the common good.

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[142] See CBC, Redefining Dementia in Denmark, CBC, <www.cbc.ca/thesundayedition/shows/2012/11/14/redefining-dementia-in-denmark/?>

[143] Barry Hoffmaster, "What does Vulnerability mean?" 2006 Hastings Centre Report 38, at 42.

## Chapter 4: Limitations on the Right to Autonomy in Relation to Medical Treatment Decision-Making

Bioethicist Robert Veatch writes:

> "At the level of law no competent patient in the United States has ever been forced to undergo medical treatment for his or her own good. I am convinced that this is ethically correct as well. No matter how tragic autonomy should always win if its only competitor is the paternalistic form of beneficence."[144]

However, the right to autonomy is not without limitations. In relation to medical treatment, the exercise of this right may be limited where there is a public health concern, in cases of medical emergency or where the capacity to be autonomous is in question. These circumstances were addressed as follows by Denham J in the Irish Supreme Court in *In Re a Ward of Court*:

> "Medical treatment may not be given to an adult person of full capacity without his or her consent. There are a few rare exceptions to this e.g., in regard to contagious diseases or in a medical emergency where the patient is unable to communicate. This right arises out of civil, criminal and constitutional law...If the patient is a minor the consent may be given on their behalf by parents or guardians. If the patient is incapacitated by reason other than age, then the issue of capacity to consent arises."[145]

For the purposes of this thesis, I will not address the limitation of the right to autonomy in relation to public health concerns. I am loath to consider that an ACD could apply if there were serious concerns about contagion. While I am not aware of any Irish precedent on

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[144] Veatch, "Overriding Autonomy", *supra* note 108 at 42.
[145] *In Re a Ward of Court*, *supra* note 14 at 156.

the imposition of medical treatment in such cases, there is a statutory basis for the lawful detention of persons with infectious diseases.[146]

The use of ACDs is most relevant in relation to the anticipation of diminished capacity to make medical treatment decisions. The concern that treatment wishes would not be followed in such a scenario is not unfounded, particularly given the precedent on this matter under Irish law and relevant decisions from other common law jurisdictions. The recent decision of the Irish High Court in *Fitzpatrick v FK* set out a rigorous approach to the assessment of capacity in relation to medical treatment decision-making.[147] I will examine this precedent in this chapter.

## 4.1 Relevant Decisions from Other Jurisdictions

Although this is not a comparative law thesis, I believe that it is a worthwhile exercise to briefly examine how the issue of the validity of medical treatment decision-making is treated in other jurisdictions, even if only for the purpose of a persuasive argument in relation to the use of ACDs. Much of this case law was reviewed by the Irish Court in *Fitzpatrick v FK*, where the Court stated as follow in relation to this jurisprudence:

> "A consistent thread in the authorities is a recognition of society's interest in preserving life if at all possible, notwithstanding that in the ultimate the right of the individual is paramount. But there is also a consistent thread that a court should act with caution where there is a conflict between society's interest in preserving life and the individual's right of self-determination."[148]

Precedents from other jurisdictions provide a background to the reasoning of the Irish High Court in *Fitzpatrick v FK*.

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[146] See section 38, Ireland, Health Act 1947, as discussed in *VTS v Health Service Executive* [2009] IEHC 106.

[147] *Fitzpatrick v FK*, *supra* note 4.

[148] *Ibid* at 37.

### 4.1.1 ***Re T (Adult: Refusal of Medical Treatment)***[149]

The United Kingdom law on the right to consent to or refuse medical treatment has a similar foundation to the Irish law, being that "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."[150] In the case of *Re T*, the United Kingdom Court of Appeal set out the principles according to which the legal validity of an adult patient's refusal is to be determined.[151] The decision of Court of Appeal provides guidance for hospital authorities and the medical profession on the appropriate response to a refusal by an adult to accept medical treatment.

*Re T* concerned the refusal of treatment on the grounds of religious beliefs. Ms T was brought to hospital following a car accident; she was 34 weeks pregnant at the time and although raised by her mother in the Jehovah's Witness faith, she herself was not a member of that faith. Following an emergency Caesarean section, Ms T began to haemorrhage and it was the opinion of the hospital staff that she required a blood transfusion in order to stabilise her condition. Prior to the surgery, Ms T had signed a consent form refusing a blood transfusion. The contents of the form were not explained to Ms T. It was also not explained to Ms T that the blood transfusion was necessary to preserve her life.[152] An emergency application was made to the English High Court by Ms T's father seeking approval to carry out the transfusion on the basis the Ms T's refusal was not valid.

The Court heard evidence from hospital staff that Ms T had been under the influence of strong painkilling medication at the time of signing the form, she was unaware of the critical nature of her condition and she was not "fully rational" at the time of signing the

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[149] *Re T (adult: refusal of medical treatment)* [1992] 4 All ER 649 [*Re T*].
[150] *Ibid* at 652 (Lord Donaldson MR).
[151] *Fitzpatrick v FK*, *supra* note 4.
[152] *Re T*, *supra* note 149 at 655.

refusal.[153] In those circumstances, the Court, per Ward J, found that the refusal of consent was a refusal in form only and not in reality. [154] On a second hearing of the matter, Ward J found that Ms T had capacity to make a decision but she had been misinformed as to the availability and effectiveness of alternative procedures and therefore had neither properly consented to nor refused the transfusion.[155] By the second hearing, Ms T was sedated and no longer able to communicate her wishes and the Court found that, in those circumstances, despite the absence of her consent, it was lawful for the doctors to treat Ms T in whatever way they considered to be in her best interests.[156]

On appeal, Lord Donaldson set out the following principles in respect to the refusal of medical treatment:

> "1. Prima facie every adult has the right and capacity to decide whether or not he will accept medical treatment, even if a refusal may risk permanent injury to his health or even lead to premature death. Furthermore, it matters not whether the reasons for the refusal were rational or irrational, unknown or even non-existent. This is so notwithstanding the very strong public interest in preserving the life and health of all citizens. However the presumption of capacity to decide, which stems from the fact that the patient is an adult, is rebuttable.
>
> 2. An adult patient may be deprived of his capacity to decide either by long term mental incapacity or retarded development or by temporary factors such as unconsciousness or confusion or the effects of fatigue, shock, pain or drugs.[157]
>
> 3. If an adult patient did not have the capacity to decide at the time of the purported refusal and still does not have that capacity, it is the duty of the doctors to treat him in whatever way they consider, in the exercise of their clinical judgment, to be in his best interests.

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[153] *Re T*, *supra* note 149 at 656.

[154] *Ibid* at 657.

[155] *Ibid* at 660.

[156] *Ibid* at 659.

[157] The significance of this principle is that it provides for a finding of incapacity where there is temporary or fluctuating capacity. In my opinion, it is in these circumstances where the use of ACD is most pertinent.

4. Doctors faced with a refusal of consent have to give very careful and detailed consideration to what was the patient's capacity to decide at the time when the decision was made. It may not be a case of capacity or no capacity. It may be a case of reduced capacity. What matters is whether at that time the patient's capacity was reduced below the level needed in the case of a refusal of that importance, for refusals can vary in importance. Some may involve a risk to life or of irreparable damage to health. Others may not.[158]

5. In some cases doctors will not only have to consider the capacity of the patient to refuse treatment, but also whether the refusal has been vitiated because it resulted not from the patient's will, but from the will of others. It matters not that those others sought, however strongly, to persuade the patient to refuse, so long is in the end the refusal represented the patient's independent decision. If, however, his will was overborne, the refusal will not have represented a true decision. In this context the relationship of the persuader to the patient - for example, spouse, parents or religious adviser - will be important, because some relationships more readily lend themselves to overbearing the patient's independent will than do others.

6. In all cases doctors will need to consider what is the true scope and basis of the refusal. Was it intended to apply in the circumstances which have arisen? Was it based upon assumptions which in the event have not been realised? A refusal is only effective within its true scope and is vitiated if it is based upon false assumptions.

7. Forms of refusal should be re-designed to bring the consequences of a refusal forcibly to the attention of patients.

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[158] In relation to the fourth principle, Laffoy J, of the Irish Court, in her decision in *Fitzpatrick v FK*, *supra* note 4 at 30, offered the following clarity:

"In my view, Lord Donaldson, who clearly recognised the presumption in favour of capacity, was saying no more than that, where the patient's choice is of death over life, the question for the doctor is whether the patient has the capacity at the time to make a decision of that gravity."

> 8. In cases of doubt as to the effect of a purported refusal of treatment, where failure to treat threatens the patient's life or threatens irreparable damage to his health, doctors and health authorities should not hesitate to apply to the courts for assistance."[159]

These principles were considered by the Irish High Court in the case of *Fitzpatrick v FK* and most were adopted into Irish law where applicable to the facts of *Fitzpatrick*, which I will discuss below in section 4.2. I also believe that these principles are applicable to an ACD that is "a declaration of intention never to consent in the future or never to consent in some future circumstances."[160]

### 4.1.2 ***Re C (Adult: Refusal of Medical Treatment)***[161]

In *Fitzpatrick v FK*, there was consensus among the parties that the relevant test under Irish law for capacity to refuse medical treatment is the test set out in the English High Court decision of *Re C*.[162]

The facts of *Re C* concerned C, an inmate of Broadmoor High Security Psychiatric Hospital, who was suffering from paranoid schizophrenia and who had developed gangrene of the foot with a prognosis that amputation was required to save his life. C did not want the amputation carried out and, when the hospital refused to give an undertaking that they would not amputate under any circumstances, C applied for an injunction restraining the hospital from carrying out an amputation without his express consent. The application was successful.

On the question of the standard of capacity that enables an individual to refuse treatment, Thorpe J in the English High Court stated as follows:

> "I think that the question to be decided is whether it has been established that C's capacity is so reduced by his chronic mental illness that he does not sufficiently

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[159] *Re T*, *supra* note 149 at 664-665.
[160] *Re C (adult: refusal of medical treatment)* [1994] 1 All ER 819 [*Re C*] at 823.
[161] *Ibid*.
[162] *Fitzpatrick v FK*, *supra* note 4at 31.

> understand *the nature, purpose and effects* of the proffered amputation. I consider helpful Dr. Eastman's analysis of the decision-making process into three stages: first, *comprehending and retaining treatment information*, second, *believing it* and, third, *weighing it in the balance to arrive at choice*."[163][emphasis added]

Thorpe J continued:

> "Although his general capacity is impaired by schizophrenia, it has not been established that he does not sufficiently understand the nature, purpose and effects of the treatment he refuses. Indeed, I am satisfied that he has understood and retained the relevant treatment information, that in his own way he believes it, and that in the same fashion he has arrived at a clear choice."[164]

Thorpe J arrived at his decision on the facts, finding that C had passed all three elements of the test, having heard oral evidence from three consultant psychiatrists and from C.

### 4.1.3 ***Re MB (Medical Treatment)***[165]

The test in *Re C* was applied by the English High Court in the case of *Re MB*.

*Re MB* concerned a pregnant patient who had been advised by physicians to have a Caesarean section following diagnosis of obstetric complications which meant that vaginal delivery posed a risk to the unborn child. MB agreed to the procedure and signed a consent form but withdrew her consent just before the anaesthetic was administered as she felt panicked due to a severe phobia of needles. The High Court granted an emergency order to carry out the surgery, which the patient appealed. On appeal, the Court of Appeal applied the test from *Re C*.

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[163] *Re C, supra,* note 160 at 824.

[164] *Ibid* at 824. In relation to the evidence of the psychiatrists, Thorpe J stated: "Amongst the experts, my very clear conclusion is that the opinion of Dr. Eastman and Dr. Gall is to be preferred. They did not find any direct link between C.'s refusal and his persecutory delusions, nor was any to be found in C.'s oral evidence. Furthermore, it was clear to me that C. was quite content to follow medical advice and to co-operate in treatment appropriately as a patient as long as his rejection of amputation was respected." See *Re C, supra,* note 160 at 822.

[165] *Re MB (Medical Treatment)* [1997] 2 FLR 426 [*Re MB*].

In her judgment, Butler-Sloss LJ reiterated the principle that a competent patient who has capacity to decide may "for religious reasons, other reasons, for rational or irrational reasons, or for no reason at all" choose not to have medical intervention even though the consequences may be her own death or, in the case of pregnancy, the death of the unborn child.[166] On the facts, Butler-Sloss LJ found that MB was temporarily incompetent, as she was suffering from an impairment of her mental functioning, being her phobia, which rendered her unable to make a decision in relation to medical treatment. In these circumstances, the doctors were free to administer an anaesthetic if that was in her best interests.[167]

The doctors in *Re MB* had described MB's fear as "irrational". Butler-Sloss LJ clarified the meaning of "irrationality" in the context of capacity, distinguishing it from misperception of misunderstanding, saying:

> "Irrationality is here used to connote a decision which is so outrageous in its defiance of logic or of accepted moral standards that no sensible person who had applied his mind to the question to be decided it could have arrived at it. As Kennedy and Grubb (Medical Law, Second Edition 1994) point out, it might be otherwise if a decision is based on a misperception of reality (e.g. the blood is poisoned because it is red). Such a misperception will be more readily accepted to be a disorder of the mind. Although it might be thought that irrationality sits uneasily with competence to decide, panic, indecisiveness and irrationality in themselves do not as such amount to incompetence, but they may be symptoms or evidence of incompetence. The graver the consequences of the decision, the commensurately greater the level of competence is required to take the decision."[168]

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[166] *Re MB*, *supra* note 165 at 436. The issue of danger to the unborn child would be approached differently by an Irish court as necessitated by the Constitutional protection for the unborn under Article 40.3.3, which provides "The State acknowledges the right to life of the unborn and, with due regard to the equal right to life of the mother, guarantees in its laws to respect, and, as far as practicable, by its laws to defend and vindicate that right."

[167] *Ibid* at 437.

[168] *Ibid*.

This understanding of irrationality, applied subsequently by the Irish courts,[169] is distinct from misunderstanding or misperception of the information material to the decision-making process.[170] There is a fine line between the two concepts; I believe that the Court in *Re MB* is saying that a refusal of treatment need not be sensible but it must not be delusional. An example of irrationality not amounting to incapacity is illustrated in the facts and findings of the following case of *St George's Healthcare and NHS Trust v S*.

### 4.1.4 ***St George's Healthcare and NHS Trust v S***[171]

This case concerned the capacity of a pregnant woman, Ms S, to make decisions in relation to her medical treatment. Ms S had not sought any ante-natal care until very late in her gestation, at 36 weeks. She was diagnosed as at risk for pre-eclampsia and advised on the need for an induced delivery; S understood the risks but wanted to proceed with a natural birth.[172] Health care practitioners had concerns about Ms S's capacity to make medical treatment decisions and Ms S was involuntarily admitted, under the relevant English mental health legislation, to a mental health facility. Ms S subsequently transferred to a general health facility, where she continued to refuse to consent to the induced delivery and where the health care practitioners continued to have concerns about this refusal of treatment. An application was made to court, *ex parte*, seeking an order to carry out the induced delivery without the consent of S. The order, which was granted, was appealed by Ms S.

The Court of Appeal concluded that there was not sufficient evidence from which to conclude that Ms S's competence was less than required.[173] The evidence presented to the Court in relation to Ms S's capacity included as follows:

> "Dr. Jeffreys noted that she appeared to "fully understand" the interventions proposed, the reasons for them and the serious, life threatening, consequences of

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[169] *Fitzpatrick v FK*, *supra* note 4.
[170] *Ibid* at 35.
[171] *St George's Healthcare and NHS Trust v S* [1998] 3 WLR 936 [*NHS v S*].
[172] *Ibid* at 942.
[173] *NHS v S*, *supra* note 171 at 949

> refusal, and at the end of the examination recorded that M.S.'s capacity to consent to treatment 'appears to be intact' and expressed the opinion that her 'mental state is not affecting her capacity to consent.'"[174]

The Court was scathing of the actions of the health care practitioners in making the application in this matter, given the physicians' findings in relation to Ms S's capacity and stressed that no such application should be made where the patient is competent to accept or refuse treatment.[175] The Court set out guidelines to be applied by health care authorities and practitioners in relation to seeking court guidance on the issue of capacity to consent to or refuse medical treatment. As part of these guidelines, the Court stated, in *obiter*, that where a patient has given an advance directive, before becoming incapable, treatment should normally be subject to the advance directive; however, if there is reason to doubt the reliability of the advance directive, then an application for a declaration may be made to court. The Court did not elaborate on what would cast doubt on the reliability of an ACD.[176]

### 4.1.5 ***Re B (Adult: Refusal of Treatment)***[177]

This case concerned the lawfulness of patient's request for removal of life support. Following a period of hospitalisation due to spinal cord problems, Ms B executed a living will,[178] a form of ACD, the terms of which stated that she wished for treatment to be withdrawn if she was suffering from a life-threatening condition, permanent mental impairment or permanent unconsciousness. After suffering further illness that caused paralysis from the neck down, Ms B requested the removal of the ventilator that was assisting her breathing. The physicians caring for Ms B informed her that the terms of her living will were not specific enough to cover the removal of the ventilator and applied to

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[174] *NHS v S*, *supra* note 171 at 946. Although not referred to expressly by the Court as a reason for the finding of capacity, S was a qualified veterinary nurse and was familiar with the medical terminology used in relation to the proposed treatment.

[175] *Ibid* at 968. The Irish High Court accepted this approach in the decision of *Fitzpatrick v FK*. See *Fitzpatrick v FK*, *supra* note 4 at 92.

[176] *NHS v S*, *supra* note 171 at 968.

[177] *Re B (Adult: Refusal of Treatment* [2002] 2 All ER 449 [*Re B*].

[178] See Section 5.4. The decision in *Re B* does not contain any explicit guidance on the use of ACD.

the English High Court seeking guidance as to whether Ms B had the required capacity to validly request removal of the artificial ventilation.

The High Court found that Ms B had the requisite capacity to make this decision in relation to her care. This conclusion was largely based on assessments of Ms B carried out by consultant psychiatrists, but also on Ms B's own demeanour and evidence presented to the Court. In relation to the latter, Butler-Sloss LJ stated:

> "Her wishes were clear and well–expressed. She had clearly done a considerable amount of investigation and was extremely well-informed about her condition. She has retained a sense of humour and, despite her feelings of frustration and irritation which she expressed in her oral evidence, a considerable degree of insight into the problems caused to the Hospital clinicians and nursing staff by her decision not to remain on artificial ventilation. She is, in my judgment, an exceptionally impressive witness. Subject to the crucial evidence of the consultant psychiatrists, she appears to me to demonstrate a very high standard of mental competence, intelligence and ability."[179]

It appears from the facts of the case, that the institution was perhaps taking an overcautious approach to Ms B's request in applying for guidance from the Court. Of particular importance, in my opinion, is the guidance given by the Court in relation to the gravity of the decision, where Butler-Sloss LJ 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 and the assessment of capacity should be approached with this firmly in mind. The doctors must not allow their emotional reaction to or strong disagreement with the decision of the patient to cloud their

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[179] *Re B*, *supra* note 177.

judgment in answering the primary question whether the patient has the mental capacity to make the decision."[180] [emphasis added]

This quote highlights a recognised concern that an assessment of incapacity may be more likely where there are grave consequences to person's decision on their life or health.[181] The guidance of Butler-Sloss LJ in relation to this matter follows the approach to autonomy suggested by Beauchamp and Childress, who rejected a sliding scale assessment of capacity in relation to the consequences of a decision, stating that it "is confusing to blend a decision's complexity or difficulty with the risk at stake."[182] Instead, Beauchamp and Childress recommend that a sliding scale approach is taken in respect of the *evidence* required for the assessment of capacity; that is, the graver the consequences, the clearer and better the evidence required.[183] I would suggest that this is the correct approach, and indeed it appears to be the approach taken by the Irish and English courts.[184]

### 4.1.6 ***Malette v Shulman***[185]

This decision of the Ontario Court of Appeal concerns the significance of an ACD for a patient who is experiencing temporary incapacity. The Ontario Court applied the principle that a competent adult was generally entitled to reject medical treatment, even if the decision entailed risks as serious as death and appeared to be mistaken in the eyes of the medical profession.

Ms Malette, a Jehovah's Witness, was severely injured in a car accident and brought to hospital unconscious. A nurse found an advance directive card in Ms Malette's purse,

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[180] *Re B*, *supra* note 177 at 474. This approach by Butler-Sloss LJ is in apparent contradiction to her earlier approach in *Re MB*, supra note X where she stated that "The graver the consequences of the decision, the commensurately greater the level of competence is required to take the decision." Re B is the more recent decision, and I would take the approach in *Re B* to be the correct approach.

[181] Loren H Roth, Alan Meisl & Charles W Lidz, "Tests of Competency to Consent to Treatment", (1977) 134:3 American Journal of Psychiatry 279 at 283.

[182] Beauchamp & Childress, *supra* note 106 at 117.

[183] *Ibid*.

[184] See section 5.4.4 in relation to the importance of clarity to a valid ACD.

[185] *Malette v Shulman*, *supra* note 104.

which card was signed by Ms Malette and on which she requested that no blood or blood products be administered to her "under any circumstances". The card stated that she, Ms Malette, fully realised the implications of her position but had resolutely decided to obey the dictates of her religion as they related to the use of blood products. The card also stated that she had no religious objection to the use of non-blood alternatives. Notwithstanding the advance directive card, the treating physician, Dr Shulman, administered blood transfusions to Ms Malette, being of opinion that the transfusions were necessary to save her life. Ms Malette recovered and successfully pursued a battery claim against Dr Shulman.[186]

Dr Shulman argued that he was obliged to carry out the transfusions, despite Ms Malette's advance directions, as a decision to refuse treatment could only relive a physician of their duty to treat that patient if the decision was made consciously and contemporaneously, after having been fully informed by the physician of the risks of that decision. This argument was rejected by the Ontario Court of Appeal, where Robbins JA stated:

> "The patient manifestly made the decision on the basis of her religious convictions. It is not for the doctor to second-guess the reasonableness of the decision or to pass judgment on the religious principles which motivated it. The fact that he had no opportunity to offer medical advice cannot nullify instructions plainly intended to govern in circumstances where such advice is not possible. *Unless the doctor had reason to believe that the instructions in the Jehovah's Witness card were not valid instructions in the sense that they did not truly represent the patient's wishes, in my opinion he was obliged to honour them*. He had no authorisation under the emergency doctrine to override the patient's wishes. In my opinion, she was entitled to reject in advance of an emergency a medical procedure inimical to her religious values."[187] [emphasis added]

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[186] Battery is a claim in tort seeking recourse for non-consensual contact.

[187] *Malette v Shulman*, *supra* note 104 at 336.

The italicised quote is, in my opinion, the essence of the Court's decision in relation to the defendant's argument on the informed nature of the decision. The Court found that the doctor's doubt about the validity of the card was not rationally founded on evidence before him, with Robbins JA stating:

> "In short, the card on its face set forth unqualified instructions applicable to the circumstances presented by this emergency. In the absence of any evidence to the contrary, those instructions should be taken as validly representing the patient's wishes not to be transfused. If, of course, there were evidence to the contrary – evidence which cast doubt on whether the card was a true expression of the patient's wishes – the doctor, in my opinion, would be entitled to proceed as he would in the usual emergency case."[188]

This leaves open the possibility that there may be such circumstances which could cast doubt the validity of an ACD, but the Ontario Court did not pronounce on the nature of such circumstances. The Court found that was no basis in evidence to indicate that the ACD did not represent the current intention and instructions of Ms Malette and that there was nothing to provide support for questioning the contemporaneous strength of Ms Malette's religious beliefs, the circumstances under which the card was signed, or her state of mind at the time of signing the card. On the basis of this ruling it could be speculated that where an ACD is being applied, a physician should take into consideration any evidence, should same exist, in relation to the state of mind of the individual at the time of formalising the ACD (including of course the actual state of mind of the individual at such time.)[189]

The Irish Courts have agreed in principle with the approach in *Malette v Shulman*. In *Fitzpatrick v FK*, Laffoy J referred to *Malette v Shulman* and stated that "in principle, the instructions of a patient not to transfuse given verbally to a doctor, even in an emergency,

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[188] *Malette v Shulman*, *supra* note 104 at 337

[189] I will address this issue further in section 5.4.2.

should be followed unless there is evidence to cast doubt on the capacity of the patient to give instructions at the time."[190]

## 4.2 Irish Jurisprudence: *Fitzpatrick v FK*[191]

In my opinion, the most relevant Irish decision in relation to the limitation of the right to autonomy as it applies to medical treatment decision-making is the recent case of *Fitzpatrick v FK*. This case is particularly relevant as it concerns both the previously expressed wishes of a patient and a finding of incapacity despite the absence of any diagnosed mental health disorder or intellectual disability.[192] I have set out below a detailed summary of the facts of the case, as they bear particular importance to the decision of the High Court.

### 4.2.1 The Background Facts

This case involved a 23 year old woman, FK, who suffered a "massive post partum haemorrhage"[193] after giving birth to a healthy baby boy in a Dublin maternity hospital. Ms K was a foreign national from the Democratic Republic of Congo, without any identifiable family members in Ireland at the time of the birth; she was accompanied by a friend who also acted as an interpreter as Ms K did not speak English.[194] The medical personnel were immediately concerned with resuscitating and stabilising Ms K, which process necessitated a blood transfusion to replace the large blood loss experience by Ms K.[195] The medical team were only informed at the time the emergency situation arose that Ms K would not accept a transfusion as it was against her religious beliefs, being a Jehovah's Witness; Ms K had notified the hospital that her religion was Roman Catholic

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[190] *Fitzpatrick v FK*, *supra* note 4 at 26.

[191] *Fitzpatrick v FK*, *supra* note 4.

[192] As defined by Irish mental health legislation. See section 5.1.3.

[193] *Fitzpatrick v FK*, *supra* note 4 at 53.

[194] This is relevant as there was no partner or family member present to advocate on Ms K's behalf or indeed to act as a substitute decision maker. It subsequently came to light that Ms K's husband was in Ireland at the time of the birth and indeed was at the hospital around the time when the transfusion was being carried out. *Fitzpatrick v FK*, *supra* note 4 at 23.

[195] Although there was a resuscitation process, Ms K did not lose consciousness.

when she had registered there before the birth. The resuscitation and stabilisation process continued for approximately one and a half hours, during which time Ms K persisted in her refusal to accept a blood transfusion.[196] Four incidences of these refusals were recorded on Ms K's chart during this time. [197]

The medical team reviewed alternative therapies, but concluded that Ms K would die without the blood transfusion. Dr Chris Fitzpatrick, the most senior obstetrician in the hospital (the Master), who became involved in the matter after the haemorrhage occurred, was concerned about the "quality" of Ms K's refusal and the consequences of the refusal and he, and the other treating obstetrician, proceeded with an *ex parte* application to the High Court seeking an order to transfuse Ms K. It was acknowledged by the plaintiffs that at the time of making the application Ms K was *not* "*non compos mentis*".[198]

Following a very brief hearing, Abbott J in the High Court made the following order:

> "It is ordered that the plaintiffs be authorised to administer to the defendant, including all appropriate steps by way of restraint or otherwise, all appropriate medical treatment and other ancillary procedures including blood transfusion and clotting agents."[199]

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[196] There was no issue in relation to the standard of care met by the hospital staff in managing the bleed. *Fitzpatrick v FK*, *supra* note 4 at 53.

[197] These notes stated: "Explained to patient re need for blood transfusion. Same refused and patient voiced that she is a Jehovah's Witness and will not take blood; Patient asked again for permission to give blood transfusion. Refused same, aware of complications. ;Hb [haemoglobin] 5.1 mmols [millimoles]. Same explained to patient and aware of consequences of not taking blood transfusion. Refused same.; Explained again to [Ms. K] re need for blood transfusion. Refused.". See *Fitzpatrick v FK*, *supra* note 4at 55. The Court disregarded these contemporaneous notes made by a student nurse, based on the evidence of the attending obstetricians, as the notes conflicted with the account of the obstetricians, who were not convinced as to the validity of Ms K's refusal. See *Fitzpatrick v FK*, *supra* note 4 at 57

[198] *Fitzpatrick v FK*, *supra* note 4 at 20. To be *compos mentis* means to be of sound mind and usually is applied in relation to mental illness. It is an antiquated term that has no definition in current Irish mental health or capacity legislation and its continued use makes for an unfortunate lack of clarity. However, in this context, I am taking it to infer mental and legal capacity. See *Fitzpatrick v FK*, *supra* note 4 at 57. Later in the judgment, the Court states that "(i)n the course of informing the court about the emergency, counsel informed the court that it was the opinion of the Hospital that Ms. K was *compos mentis*." This is obviously different to "not non compos mentis"; it is a more weighted in favour of capacity. See *Fitzpatrick v FK*, *supra* note 4 at 42.

[199] *Ibid* at 14.

Unfortunately there is no written decision of Abbott J in this matter; however, a written attendance note was taken by lawyers present at the hearing. This attendance note recorded that Abbott J applied the following considerations before making the order:

> "He remarked on the fact that Ms. K was conscious. He acknowledged that the case involved a life or death situation and that, if Ms. K were present in court on a stretcher, she would object to the administration of the treatment... counsel submitted that there would be no difficulty or no question if Ms. K was unconscious. However, there was a real risk that she would slip into unconsciousness and that she would subsequently die."[200]

The plaintiffs argued that their concerns about the quality of Ms K's refusal were based on the following factors: the assumption that Ms K was a Roman Catholic, the language barrier and the apparent absence of the other parent in the country.[201] Counsel for the plaintiffs "made it clear that he was not suggesting that Ms K was incompetent to make the decision, but suggested that 'the question was open to the court as to what extent her refusal was made on the basis of an informed decision'".[202] Abbott J stated that he was of the view that Ms K was "competent".[203] According to the attendance note of the decision, Abbott J. stated that he was prepared to override Ms K's decision in spite of her capacity on the grounds that the welfare of the child was paramount, being newly born with no apparent parent in the country other than Ms K.[204] Abbott J also stated that he was erring on the side of the preservation of life.[205]

Ms K was sedated and given the blood transfusion within an hour of the making of the High Court order. Before sedation, Ms K remained adamant that she did not want a blood

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[200] *Fitzpatrick v FK*, *supra* note 4 at 43. This attendance note was accepted in evidence at the plenary hearing of the matter.

[201] *Ibid* at 43- 44.

[202] *Ibid* at 44

[203] *Ibid* at 45.

[204] *Ibid*. This is an extraordinary finding by the High Court, especially given the finding in relation to capacity. Procedurally, the Court held that the fact that the *ex parte* order was made with regard to the rights of Ms K's baby, even though it was factually inaccurate, did not render the blood transfusion unlawful. See *Fitzpatrick v FK*, *supra* note 4 at 101.

[205] *Ibid* at 45.

transfusion and "was upset and agitated".[206] Ms K subsequently made a full recovery and was discharged from hospital.

### 4.2.2 The Plenary Hearing

Following the *ex parte* application, the plaintiffs proceeded with plenary proceedings against Ms K seeking declaratory reliefs that they had been entitled to apply for the Order.[207] In the plenary hearing, the plaintiffs asserted that Ms K had not been "in a position to make a fully informed decision to refuse consent to the medical procedures necessary to save her life."[208] Ms K issued a counterclaim denying this assertion, along with a denial that a blood transfusion was necessary to save her life.[209] Ms K further asserted that she was entitled to refuse medical treatment as part of her rights to autonomy and bodily integrity and that the transfusion amounted to an assault and trespass to her person.

At the plenary hearing, Laffoy J identified the core issue as:

> "(W)hether and, if so, in what circumstances, a court may intervene in the case of a patient, who is an adult and is not *non compos mentis*, who has refused medical treatment, and by order authorise the hospital and its personnel in which he or she is a patient to administer such treatment to the patient."[210]

This was the first time such an issue was addressed by an Irish Court. The issue had been partially dealt with in *obiter* by the Court in *In Re a Ward of Court*, which I have discussed in Chapter Two.[211]

The Court in Fitzpatrick set out that there were two issues to be decided, being:

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[206] *Fitzpatrick v FK*, *supra* note 4 at 15.

[207] Although it is not stated in the judgment, I suggest that these proceedings were possibly pre-emptively pursued to bring legal clarity to this issue for the plaintiffs and in anticipation of any action that could have been brought by Ms K.

[208] *In Re a Ward of Court*, *supra* note 14 at 15.

[209] *Ibid* at 17. The Court concluded, on the basis of the evidence, that the blood transfusion was the appropriate treatment. *Fitzpatrick v FK*, *supra* note 4 at 79.

[210] *Fitzpatrick v FK*, *supra* note 4 at 15.

[211] *In Re a Ward of Court*, *supra* note 14 at 160.

a) Whether Ms K had given a legally valid refusal of treatment which turned on Ms K's capacity to make a decision to refuse at the time she articulated the refusal, (the "capacity question"); and

b) If Ms K had capacity to make a valid decision to refuse treatment, whether the Court was entitled to have regard to her baby's constitutional rights and to balance these rights against Ms K's constitutional rights (the "balancing of rights" question).[212]

### 4.2.3 The Capacity Question: "Comprehending and retaining treatment information, believing it; and, weighing it in the balance to arrive at choice"[213]

The plaintiffs' statement of claim set out the factors giving rise to their concern that Ms K might not have been in a position to make a fully informed decision to refuse treatment. These factors were:

a) Ms K had registered with the hospital as a Roman Catholic;

b) the Hospital had only been informed that Ms K was a Jehovah's Witness subsequent to the haemorrhage;

c) the potential communication difficulties, as English was not Ms K's native tongue and she had to rely an interpreter; and

d) the concern that Ms K might not have fully recognised the seriousness of her condition, in that she might not have fully appreciated the lack of any additional alternative treatments to a blood transfusion.[214]

While only factors (a) to (c) were expressly argued at the *ex parte* hearing, the Court, at plenary hearing, accepted that factor (d) *was* part of the case made to Abbott J as it was implicit in the facts and submissions put before the Court at the *ex parte* hearing.[215]

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[212] *In Re a Ward of Court*, *supra* note 14 at 20.

[213] This the test for capacity as set out in *Re C*, *supra* note 160.

[214] *Fitzpatrick v FK*, *supra* note 4 at 47.

### i. The Test for Capacity:

The Court agreed with the parties that the correct test for capacity in relation to medical treatment decision-making was the test applied by the English High Court in *Re C*.[216] In relation to the application of this test by an Irish Court, Laffoy J stated:

> "What the law, as set out in the *C* case, requires is that the patient be given the relevant information about his or her condition, the proposed treatment, any alternative treatment available and the likely outcome of adopting such options as are open to the patient. In a case in which the doctor considers that a blood transfusion is necessary to save the patient's life and that without it the patient will die, that is the information which the patient has to be given, as counsel for Ms. K acknowledged. But it is also the information which the patient has to assimilate, has to believe and has to factor into the decision making process. Article 40.3 protects life and requires that, as does the common law. If the patient is not given the relevant information or, alternatively, fails to assimilate it and believe it, the first two elements of the *C* case test are not fulfilled. If the patient does assimilate and believe the information but nonetheless rejects the treatment on the basis of a religious conviction, for example, adherence to a scriptural proscription on accepting the treatment, he or she has passed the *C* case test as to capacity notwithstanding that the doctor and non-believers may consider the basis of his or her refusal to be wholly irrational."[217]

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[215] *Fitzpatrick v FK*, *supra* note 4 at 47. I do not agree with this part of the Court's decision but any such criticism lies in the idiosyncrasies of the Irish rules of pleading and is not relevant to the discussion here. It is sufficient to say here that I believe that this decision on pleadings could have been challenged, and maybe successfully so, if the case had been appealed to a higher court, as it was expressly submitted to the Court during the *ex parte* application that Ms K *had* capacity.

[216] *Ibid* at 31.

[217] *Ibid* at 33. Laffoy J went on to state that a person's refusal of treatment on the grounds of religious belief should not simply be accepted by the treating hospital personal without considering the capacity of the patient to understand their medical condition, as this would ignore the second element of the test from *Re C*. See *Fitzpatrick v FK*, *supra* note 4 at 33.

The Court then set out the principles for the assessment of capacity that should be applied by an Irish court, which principles are based on authorities from other jurisdictions and from the Irish constitutional framework. These principles are as follows:

> *"*(1) There is a presumption that an adult patient has the capacity, that is to say, the cognitive ability, to make a decision to refuse medical treatment, but that presumption can be rebutted.
>
> (2) In determining whether a patient is deprived of capacity to make a decision to refuse medical treatment whether –
>
> (a) by reason of permanent cognitive impairment, or
>
> (b) temporary factors, for example, factors of the type referred to by Lord Donaldson in *In re T. (Adult: refusal of medical treatment)* [1993] Fam. 95, 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.
>
> (3) The three stage approach to the patient's decision making process adopted in *In re C. (Adult: refusal of medical treatment)* [1994] 1 W.L.R. 290 is a helpful tool in applying that test. The patient's cognitive ability will have been impaired to the extent that he or she is incapable of making the decision to refuse the proffered treatment if the patient-
>
> (a) has not comprehended and retained the treatment information and, in particular, has not assimilated the information as to the consequences likely to ensue from not accepting the treatment,[218]

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[218] In relation to treatment, Laffoy J stated: "Therefore, in my view, the assumption which underlies the application of the *C* case test, that the treatment is necessary, means no more than that the treatment is the appropriate treatment, that is to say, that it is clinically indicated... In layman's terms the message was that

(b) has not believed the treatment information and, in particular, if it is the case that not accepting the treatment is likely to result in the patient's death, has not believed that outcome is likely, and

(c) has not weighed the treatment information, in particular, the alternative choices and the likely outcomes, in the balance in arriving at the decision.

(4) The treatment information by reference to which the patient's capacity is to be assessed is the information which the clinician is under a duty to impart - information as to what is the appropriate treatment, that is to say, 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.

(5) In assessing capacity it is necessary to distinguish between misunderstanding or misperception of the treatment information in the decision making process (which may sometimes be referred to colloquially as irrationality), on the one hand, and an irrational decision or a decision made for irrational reasons, on the other. The former may be evidence of lack of capacity. The latter is irrelevant to the assessment.[219]

(6) In assessing capacity, whether at the bedside in a high dependency unit or in court, the assessment 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.[220] In the private law context this means that, in applying the civil law standard of proof, the weight to be attached to the evidence should have regard to the gravity of the decision, whether that is characterised as the necessity

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the doctors' opinion was that a blood transfusion was necessary and that without it she might die." *Fitzpatrick v FK*, *supra* note 4 at 78-79.

[219] In relation to the alleged irrationality of Ms K's decision, Laffoy J stated: "If the totality of the evidence suggested that she understood and believed that a blood transfusion was necessary to preserve her life but, nonetheless, made a decision, on whatever grounds, which most people would regard as irrational, that decision would have to be respected." *Fitzpatrick v FK*, *supra* note 4 at 77.

[220] See my comments in relation to a sliding scale assessment of capacity, above at page 52.

for "clear and convincing proof" or an enjoinder that the court "should not draw its conclusions lightly".[221]

In my opinion, these principles are the applicable principles under Irish law in relation to the assessment of capacity in medical treatment decision-making. I examine these principles further in Chapter Four.[222]

### ii. Application of the 'Capacity Principles' to Ms K:

Laffoy J stated that the question of capacity should be determined by reference to what was known by the Hospital personnel about Ms K's condition and her circumstances at the time of the refusal.[223] In relation to this, Laffoy J stated that it was necessary to consider whether the evidence established that, at the relevant time, Ms K:

a) understood and retained the information given to her by the hospital personnel as to the necessity of a blood transfusion to preserve her life;

b) believed that information and, in particular, whether she believed that she was likely to die without a blood transfusion being administered; and

c) had weighed that information in the balance, balancing the risk of death inherent in that decision and its consequences against the availability of a blood transfusion which would preserve her life.[224]

In applying the principles of capacity to the facts, the Court stated that the question to be answered was whether the evidence demonstrated that the plaintiffs were objectively justified in doubting Ms K's capacity.[225]

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[221] *Fitzpatrick v FK*, *supra* note 4 at 40-42.

[222] See section 5.1.

[223] *Fitzpatrick v FK*, *supra* note 4 at 47.

[224] *Ibid* at 48. The Court stated that "(T)he essential piece of information which Ms. K had to assimilate and believe was that a blood transfusion was necessary and that without it she might die and the crucial question is whether she did so." *Fitzpatrick v FK*, *supra* note 4 at 82.

[225] *Ibid* at 48. I believe that this is the correct application of the presumption of capacity.

The first plaintiff, Dr Fitzpatrick, gave evidence on the factors which suggested to him that Ms K failed to comprehend the seriousness and precarious nature of her medical condition. These factors included the suggestion that Ms K made that she could be given cola (the soft drink) and tomatoes, as an alternative to the blood transfusion.[226] The Court interpreted this suggestion as evidence that Ms K had no real medical understanding of the nature of the situation which had confronted her.[227] Ms K's own evidence seems to indicate that she knew that this proposal was not as effective as a blood transfusion but it was an alternative that would work over time, and that she understood that her situation was a life and death situation.[228] The Court favoured the evidence of the physicians, with Laffoy J stating that "(t)he Coke and tomatoes episode is symptomatic of Ms. K's lack of understanding of the gravity of her condition."[229] Laffoy J went on to state that when viewed objectively Ms K's suggestion in relation to alternative therapies "could only ring alarm bells as to Ms. K's appreciation of the gravity of her situation and what was required to be done to preserve her life."[230] The Court clarified that this lack of understanding should not be viewed as or confused with "irrationality".[231]

The Court also heard evidence from Dr Noreen Russell, the specialist registrar in obstetrics and gynaecology. Dr Russell gave evidence that she had been concerned that Ms K did not understand the gravity of the situation and was not "convinced" that Ms K was aware of the consequences of not being transfused.[232] Dr Russell stated that "because

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[226] *Fitzpatrick v FK*, *supra* note 4 at 60. The judgment later sets out Ms K's own recount of her suggested treatment as follows:"She expressed the view that those products were very important in the human body, that tomatoes come from the earth, that they are very important because they contain vitamin A and iron, eggs also contain iron and Coca Cola contains energy. Her view was that those products would improve her blood because her parents had used them and a lot of Jehovah's Witnesses use them. However, the Master told her that he did not think the products would help." See *Fitzpatrick v FK*, *supra* note 4 at 66

[227] *Ibid* at 67

[228] *Ibid* at 68

[229] *Ibid* at 77.

[230] *Ibid* at 81

[231] *Ibid* at 77. In relation to this point, Dr Peter Boylan, an expert witness stated to the Court that he did not think that Ms K was competent as the cola and tomatoes suggestion showed, to him, that she was not position to make rational decisions. Laffoy J stated that Dr Boylan was blurring "the distinction which should be made in assessing capacity between misunderstanding or misperception of the treatment information in the decision-making process and the irrationality of the decision itself." See *Fitzpatrick v FK*, *supra* note 4 at 77.

[232] *Ibid* at 56.

she and her colleagues were communicating via an interpreter they were not getting what they would have considered the appropriate responses from Ms K, which would have suggested to them that she understood and was making a fully informed refusal."[233] The consultant haematologist, Dr Evelyn Conneally, gave evidence that she expected Ms K to be "more upset" about the situation, which raised a question for Dr Conneally as to how much Ms K understood of her situation. [234]

Ms K's own evidence was that she understood that she had been in danger of dying, "because when a doctor tells you that you are going to die, it is not a joke".[235] Later, in the context of explaining what she found so offensive about taking blood, Ms K stated that "(t)he doctors are not one hundred per cent sure that the blood is good for the person, and I am sure that later on there is effects of the blood transfusion.(sic)"[236]

A concerning aspect of the decision is the weight placed by the Court on Ms K's demeanour and inferences drawn about her credibility. The Court had regard to Ms K's credibility on the basis of apparently misleading information given to the hospital in relation to her background, with Laffoy J stating in her judgment:

> "What does bear on the capacity question is that Ms. K, on her own evidence, gave false information to the Hospital in registering as a Roman Catholic on booking in. The reason she advanced for so doing, that she thought it was necessary for consistency with her asylum application, was most unconvincing... Ms. K had ample opportunity on her many visits to the Hospital before the emergency occurred on 21st September, 2006 to correct the false information she gave the Hospital as to her religion."[237]

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[233] *Fitzpatrick v FK*, *supra* note 4 at 56.

[234] *Ibid* at 62. In my opinion, this evidence should have been dismissed, or at least highlighted, as lacking in subjectivity. No evidence was presented to the Court in relation to expected patient responses to such a situation.

[235] *Ibid* at 66.

[236] *Ibid*. In relation to Ms K's evidence, Laffoy J found that "(h)er responses demonstrated no understanding that the doctor has a responsibility to ensure that the patient has properly assimilated the advice." See *Fitzpatrick v FK*, *supra* note 4 at 67.

[237] *Ibid* at 51.

The Court also looked at the interaction between Ms K and hospital staff in relation to the whereabouts of her husband; Ms K had misinformed the hospital staff that her husband was not in the country. Ms K later told the Court that she had lied on this point as her husband was in the country illegally and she feared for the possible repercussions. The Court viewed this misinformation grimly stating: "(t)his episode raises not only a serious question about Ms. K's credibility, but also about her ability to understand the consequences of a decision to refuse a blood transfusion for her baby's future care."[238]

In my opinion, there is much to criticise in this statement, notwithstanding that it is an unsympathetic approach to the stresses on those in the asylum process, no evidence was put before the Court in relation to the psychology of non-truth telling and capacity to understand the consequences of medical treatment decisions. It was a logical leap for the Court to make this assumption about Ms K's capacity based on misleading the hospital in relation to this issue. Another concerning leap is the inferences that the Court drew from the demeanour of Ms K as a witness in the hearing. In relation to this point, Laffoy J stated: "Her demeanour gave some insight as to why the Hospital personnel who were treating her on 21st September, 2006 would have harboured doubts about her understanding of the gravity of her condition."[239]

The Court concluded that, based on the evidence available before the making of the *ex parte* application, the plaintiffs were objectively justified in doubting Ms K's capacity to

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[238] *Fitzpatrick v FK*, *supra* note 4 at 59.

[239] *Ibid* at 67. It is clear to me that the Court took a certain view on Ms K's evidence, which is a feature of the adversarial witness based system of litigation in common law courts. However, the harsh view taken by the Court in relation to Ms K's evidence undoubtedly added significantly to the conclusion of the Court in relation to the capacity question. In my opinion, this is as unfortunate as it is illuminating on the approach of the courts and medical personal to individuals coming from differing cultural backgrounds, and arguably verges on culture insensitivity. Laffoy J stated as follows: "A regrettable feature of this case is that, notwithstanding that the medical emergency which arose was not foreseeable, the intervention of the court probably could have been obviated if Ms. K had not misrepresented the facts as to her religion when booking into the Hospital and had not perpetuated the misrepresentation and compounded it by misrepresenting the position in relation to her family throughout her dealings with the Hospital. At the beginning of his testimony the Master emphasised that the Hospital is a non-denominational hospital which accommodates patients from different ethnic backgrounds and of different religious beliefs. I am satisfied on the evidence that it is a hospital in which the wishes of patients of the Jehovah's Witness faith who do not wish to be transfused are respected. The situation in which Ms. K was transfused against her wishes unfortunately was of her own making." *Fitzpatrick v FK*, *supra* note 4 at 84.

refuse a blood transfusion.[240] The Court listed the following factors which put the Hospital personnel on inquiry as to whether Ms K's refusal was valid:

> "Ms. K's seriously compromised medical status following a long labour, a difficult delivery and a massive haemorrhage;[241]the communications difficulties created by the fact that Ms. K's first language was not English; the fact that she was a young woman in a foreign country whom the Hospital personnel believed had no family members in the State to whom the Hospital could turn for some assurance or confirmation of her religion and her understanding of her need for a blood transfusion; that, if she died, on the basis of what she told the Hospital personnel her new-born baby would have no traceable next of kin and the whereabouts of his father would be unknown; and that by her disclosure, after the haemorrhage, Ms. K told the Hospital personnel for the first time that she was a Jehovah's Witness and would not take blood, which was at variance with the Hospital's understanding that she was a Roman Catholic which was based on the information she gave when booking."[242]

The Court held that the treating physicians "gave Ms. K the information necessary to enable her to make an informed decision as to whether to accept or refuse a blood transfusion" and that the information was conveyed in a manner and language " from which a competent adult whose capacity was not impaired should have understood the gravity of the situation."[243] In relation to the language barrier, the Court accepted the evidence of Ms K's translator that there was no problem in getting across the necessity of the blood transfusion to Ms K in her own language.[244]

The Court found that it was not possible, on the totality of Ms K.'s own evidence, to conclude that she understood and believed that without a blood transfusion she might

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[240] *Fitzpatrick v FK*, *supra* note 4 at 83.

[241] I am not clear as to what the Court means by the term "medical status"; it is not clear from the context whether it refers to either mental or physical health, or both.

[242] *Fitzpatrick v FK*, *supra* note 4 at 82.

[243] *Ibid* at 79.

[244] *Ibid* at 53.

die.[245] I have critical reservations about this finding on the facts, as the expert witnesses were not *ad idem* on the outcome of not receiving a blood transfusion.[246] I am not convinced that the Court posed the correct question in relation to the assessment of Ms K's capacity; *i.e.*, that she understood and believed that without a blood transfusion she might die. I think that a better approach based on the facts before the Court would have been to question whether Ms K understood that the *physicians treating her* were of the opinion that a blood transfusion was necessary in the circumstances.

### 4.2.4 The Balancing of Rights Question

The plaintiffs argued that that Ms K's baby's constitutionally protected rights would take precedence over Ms K's constitutional rights as the avoidable death of Ms K would result in leaving her baby without a parent in the State and would constitute abandonment.[247] This assertion was rejected by the defendant on the grounds that even if the baby had a constitutional right to be nurtured and reared by Ms K, this did not entitle the plaintiffs to override her autonomous refusal of medical treatment as a competent adult. It is crucial to highlight here that at no stage did Ms K's decision to refuse treatment in any way jeopardise her baby's right to life.[248] In the end, the Court did not have to pronounce on this matter as the issue as the Court found that Ms K's capacity to refuse treatment had been impaired and also because the argument was not based in the facts of the matter; the baby's father was in the country at the time of his birth, therefore the baby would not have been parentless in the country if Ms K had died, even though this was not within the knowledge of the hospital personnel caring for Ms K at the relevant time.

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[245] *Fitzpatrick v FK*, *supra* note 4 at 82.

[246] The necessity of the transfusion was a point on which the expert witnesses digressed, with a number of the witnesses concluding that the transfusion would have been the normal course of action in a patient presenting with the haemoglobin levels of Ms K at the time, but only if the patient consented. See the evidence of Dr Felicity Platt, Dr Vanessa Martlew, and Dr Malcolm Griffiths. *Fitzpatrick v FK*, *supra* note 4 at 69-74.

[247] In this respect, the plaintiffs pointed to the child's rights under Articles 40.3.1, 40.3.2, 41 and 42.5 of the Irish Constitution. See *Fitzpatrick v FK*, *supra* note 4 at 22.

[248] See *Fitzpatrick v FK*, *supra* note 4 at 22.

There is, therefore, no Irish precedent on the issue of whether the interests of a child can override those of a parent who refuses medical treatment.[249] There is guidance on this issue from the Courts in the United States, which the Court reviewed in *Fitzpatrick v FK*. In *Norwood Hospital v Yolanda Munoz* (1991) 564 Ne 2d 1017, the Supreme Court of Massachusetts held that the State's interests in protecting the wellbeing of a minor child did not override the parent's right, as a competent adult, to refuse lifesaving medical treatment.[250] I would see this as the correct approach in relation to the balancing of rights in this context.

However, there may be an argument that the autonomy of the adult parent could be overridden in the interests of the well-being of the probable orphan, if a child would be left with no guardian in the state should the parent's refusal of treatment be followed. The consequences in such a situation would have to amount to abandonment of the child in order to justify the overriding of the adult's right to autonomy.[251] This concern would clearly only arise in relation to minor children.

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[249] The Court in *Fitzpatrick v FK* stated in obiter, of court, that there was germane precedent on this issue, being the case of *AO & DL v Minister for Justice* [2003] 1 IR 1 and *North Western Health Board v HW* [2001] 3 IR 622. However, in my opinion, neither of these cases is directly on point. In *AO & DL v Minister for Justice*, the Supreme Court held that the constitutional right of an Irish born child to the company, care and parentage of their foreign national parents within the State, was not absolute and unqualified, and could be balanced against the State's inherent right, in the interests of the common good, to control immigration. *North Western Health Board v HW* concerned the refusal of parents to allow their child to undergoing a screening test for a medical condition, which refusal was based on the parents' religious beliefs. Therefore this case concerned a parental decision directly relating to the child's welfare and not the balancing of a parent's autonomy in relation to their own medical treatment against the welfare of a child.

[250] *Norwood Hospital v Yolanda Munoz* (1991) 564 Ne 2d 1017.

[251] In *Public Health Trust of Dade County v. Wons* (Fla 1989) 541 So2d96, the Supermen Court of Florida, per Erlich CJ, held that: "Absent evidence that a minor child will be abandoned, the state has no compelling interest sufficient to override the competent patient's right to refuse treatment. Sweeping claims about the need to preserve the lives of parents with minor children have an emotional appeal that facilely avoids both the constitutionally required scrutiny of the state authority to act and the search for less restrictive alternatives."

## 4.3 Conclusions on the Limitation of the Right to Autonomy in Relation to Medical Treatment

I believe that the principles listed by the Court in *Fitzpatrick v FK*, set out in full above at pages 60 to 62, are the correct approach to the assessment of capacity in relation to medical treatment decision-making. I have concerns about the application of these principles to the facts of the case and the conclusions reached by the Court, which I believe may not have adequately respected Ms K's right to autonomy. The approach of the Court appears to conflate the capacity to refuse medical treatment with the standard required for an informed refusal of treatment.[252]

The result of the decision in *Fitzpatrick v FK* is that medical treatment decisions made by an individual when not "of unsound mind" could be overturned by a doctor, or indeed a court, on the basis of a temporary loss of capacity.

Individuals, who are concerned about medical treatment decision-making being taken out of their hands on a finding of incapacity, may consider the option of formalising their treatment wishes in an ACD. There is a stark divergence in court decisions in relation to medical treatment decision-making where there is an ACD, for example, the contrast between the outcomes of *Malette v Shulman* and *Fitzpatrick v FK*. Indeed Laffoy J stated that one of the differences between the decision in *Malette v Shulman* and *Fitzpatrick v FK* was the absence of an ACD in the case of Ms K.[253]

I can only speculate that the existence of an ACD in the case of Ms K may have resulted in the Irish High Court reaching a different decision. However, it is arguable that the simple existence of an ACD would not result in the application of the ACD without scrutiny of its validity. In the next chapter I address the criteria, as I see them, of a lawful and valid ACD under Irish law.

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[252] The approach of Beauchamp & Childress in relation to this issue is that if the patient holds a false belief that is material to her decision to refuse, that refusal is not an informed refusal; however, an uninformed refusal is not a matter for capacity but instead is a "correct" exercise of autonomy. See Beauchamp & Childress, *supra* note 106 at 131.

[253] *Fitzpatrick v FK*, *supra* note 4 at 26.

## Chapter 5: A Lawful Advance Care Directive

Given the potentially limiting nature of how the law in Ireland has been applied in relation to the right to refuse medical treatment and its effects on autonomy, an individual may wish to formalise their wishes in relation to treatment in order to ensure that they would not receive treatment that is against their wishes, should they lose capacity. An option that is open to individuals in other jurisdictions is the use of advance care directives (ACDs). The Irish Medical Council defines an ACD "as a written document giving direction and guidance for healthcare decisions at a time of future incompetence."[254] The Irish Medical Council guidelines already recognise the use of ACDs, and state that "an advance treatment plan has the same ethical status as a decision by a patient at the actual time of an illness and should be respected on condition that the decision was an informed choice, the decision covers the situation that has arisen and the patient has not changed their mind."[255]

Irish law does not explicitly provide for the use of ACDs but despite this, I do not believe that their use is *prima facie* unlawful in Ireland, and I believe that a court would uphold their use, once certain conditions were fulfilled. In this chapter I would like to address, what I see, as being the criteria for a lawful ACD under Irish law. These criteria are:

- Capacity to make the ACD.
- The ACD must not request unlawful measures.
- The ACD must be clear and made voluntarily.
- It is possible that the decision to make the ACD must be informed.

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[254]Ireland, Irish Medical Council, *Advance Directives*, IMO, see online <www.medicalcouncil.ie/News-and-Publications/Publications/Discussion-Documents/Advanced-Directives.html>

[255] Ireland, Irish Medical Council, Guide to Professional Conduct and Ethics for Registered Medical Practitioners, 7th edition ( Irish Medical Council, 2009) at paragraph 41.2.

## 5.1 Capacity to Make an ACD

In order to write a valid ACD, a person must have the capacity to do so at the relevant time. Capacity is the ability to perform a given task and in a legal context it refers to the person's ability in law to make a decision with legal consequences.[256] In the case of an ACD, a Court would have regard to the capacity of the person at the time of the making of the ACD was made and should apply the presumption of capacity.[257] This presumption applies to all adults with the burden of establishing incapacity lies on the party asserting that there is a lack of capacity.[258] It is presumed that all adults have legal capacity, allowing them to enter into contracts or to make other significant life decisions.

As set out in Chapter 3, autonomy requires meaningful decision making, and a lack of capacity can be seen as a barrier to this meaningful decision making if an individual lacks the requisite ability to understand and make a meaningful choice. Therefore a crucial aspect of the lawfulness of an ACD is whether the individual has the requisite capacity at the time of making the ACD so that it can be said that they made an autonomous choice.

It is important to note that the medical definition or understanding of capacity is not the legal definition. While a medical assessment of capacity according to medical tests, such as the Mini-Mental State Examination, may aid a court in reaching a decision on capacity, it is not conclusive, and a court will reach its own conclusion on capacity based on the facts.

There are different tests for capacity under Irish law depending on the task. The question in relation to the making of an ACD is what level of capacity should be required as the degree of understanding required will vary according to the complexity of transaction.[259] I would argue that the correct level of capacity required to make an ACD is that required

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[256] Ireland, Law Reform Commission, *Report on Vulnerable Adults and the Law: Capacity* (Dublin: Law Reform Commission, 2005) at 19. [LRC Report, *Capacity*].

[257] I refer to the "making" of the ACD as opposed to execution, as execution implies the requirement or presence of formal elements.

[258] *In re Glynn Deceased* [1990] 2 IR 326; *Re T*, *supra* note 149.

[259] *Re Beaney* [1978] 2 All ER 595.

to consent to or refuse medical treatment.[260] This issue, addressed most recently by the Irish courts in *Fitzpatrick v FK*, has been discussed at length in Chapter 4. In *Fitzpatrick v FK*, Laffoy J set out the six relevant principles applicable to the determination of the capacity in relation to refusal of medical treatment.[261] I will revisit them in brief:

a) There is a presumption that an adult patient has the capacity to make a decision to refuse medical treatment, but that presumption can be rebutted.
b) In determining whether a patient is deprived of capacity to make a decision to refuse medical treatment, by cognitive, permanent or temporary reasons, 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.
c) There is a three-stage approach to applying that test. The patient's cognitive ability will be found to be impaired if they:
    a. have not comprehended and retained the treatment information and have not assimilated the information as to the consequences likely to ensue from not accepting the treatment,
    b. have not believed the treatment information, in particular, if they have not that not accepted that the refusal is likely to result in death; and
    c. have not weighed the treatment information, the alternative choices and the likely outcomes, in the balance in arriving at the decision.
d) The treatment information by reference to which the patient's capacity is to be assessed is the information which the clinician is under a duty to impart, that is information as to 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.

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[260] In *Re C*, supra note 160 at 824, Thorpe J rejected the argument that the capacity to refuse treatment is no higher than the capacity to contract.

[261] *Fitzpatrick v FK*, *supra* note 4.

e) An irrational decision or a decision made for irrational reasons is irrelevant to the assessment of capacity. However, misunderstanding or misperception of the treatment information may be evidence of a lack of capacity.
f) The assessment 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.[262]

The application of this test in *Fitzpatrick* was based on the totality of the evidence at the time of making the decisions to refuse treatment. I opine that if this test is successfully applied by an individual making an ACD, an Irish court will find that the individual had the requisite capacity for a valid ACD. This approach to capacity reflects the approach of Beauchamp and Childress to autonomy and capacity where they commented that a patient has capacity to make a decision if they have the "capacity to understand the material information, to make a judgment about this information in light of their values, to intend a certain outcome, and to communicate freely their wishes to caregivers or investigators."[263] Therefore, I propose that this is the best approach to ensuring proper autonomy in relation to the making of an ACD. It does seem to suggest however that that presumption of capacity, is not something that should be assumed without due consideration as to whether it has been displaced.

### 5.1.1 The Presumption of Capacity

The Irish Courts have, for many years, accepted and applied the presumption of capacity; the presumption and its provenance were described as follows by Leonard Shelford:

> "Reason, being the common gift to man, raises the general presumption that every man is in a state of sanity, and that insanity ought to be proved; and in favour of liberty and of that dominion which, by the law of nature, men are entitled to exercise over their own persons and properties, it is a presumption of the law of England, that every person, who has attained the age of discretion, is of sound

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[262] *Fitzpatrick v FK*, *supra* note 4 at 40-42.
[263] Beauchamp & Childress, *supra* note 106 at 113.

mind until the contrary is proven: and this holds as well in civil as in criminal cases."[264]

The presumption of capacity is reversed in two particular scenarios, namely when the Mental Health Act 2001 applies, and where a person has been declared a ward of court. I will discuss both of these below. Also the issue of capacity is undergoing extensive legal revision in Ireland, based on recommendations from research carried out by the Irish Law Reform Commission,[265] resulting in the Assisted Decision Making (Capacity) Bill 2013, which I will also discuss in the chapter.

Where the presumption of capacity has been reversed, a "presumption of continuance" is applied; this presumption switches the burden to the person asserting capacity, as once an individual had been found to lack capacity, they will be found to continue to lack capacity.[266] This presumption has been rejected by the English Courts but Irish Courts continue have not had an opportunity to assess the current status of this presumption.[267] There is precedent to support the continuing existence of such a presumption in Irish law. In the case of *In bonis Corboy: Leahy v. Corboy*, the Supreme Court addressed the issue of the presumption of capacity in relation to the drafting of a will.[268] In this case, the testator had had ongoing health issues, which were found to have affected his capacity two years prior to the drafting of the will.[269] The Supreme Court was asked to rule on the capacity of the testator at the time of drafting the will. The Court held that, as the testator's capacity had previously been in question, the presumption of capacity did not apply and that the burden of establishing that the will was valid fell on the person asserting the will's validity. In their decision on the matter, Budd J held:

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[264] Leonard Shelford, Practical Treatise on the Law Concerning Lunatics, Idiots, and Persons of Unsound Mind (Philadephia: JS Littell, 1833) at 23.

[265] See Ireland, Law Reform Commission, *Consultation Paper on Law and the Elderly* (Dublin: Law Reform Commission, 2003); LRC Report, *Capacity*, *supra* note 256.

[266] See Casey & Craven, *Psychiatry and the Law* (Dublin: Oaktree Press, 1999), at 318.

[267] *Masterman-Lister v Brutton & Co* [2002] EWCA Civ 1889.

[268] *In bonis Corboy: Leahy v Corboy* [1969] I IR 148.

[269] *Ibid* at 151.

> "It would seem to me that nothing less than firm medical evidence by a doctor in a position to assess the testator's mental capacity could suffice to discharge the onus of proving him to have been a capable testator. No doctor was brought to see him on that occasion. Such evidence as was adduced does nothing to aid matters. The testator said nothing and one does not have any material on which a judgement can be formed as to his mental capacity so far as he himself is concerned."[270]

Likewise in the case of *In re Glynn*,[271] the High Court held that where the presumption of continuance applies in the case of a will, a heavy onus shifts to the person advocating the validity of the will to show that the testator had capacity and understood the extent of his property and the nature of claims against that property.[272] In this case the testator had suffered a stroke prior to the execution of the will and this condition was found to have affected his capacity to communicate his testamentary wishes.[273]

What this precedent means for the use of ACDs is that the presumption of capacity can be overturned if there has been a question or a finding of a lack of capacity prior to the making of an ACD. This has particular significance for individuals who have been declared wards of court or who fall under the provisions of the Mental Health Act 2001.

### 5.1.2 Wardship

Currently in Ireland the only existing formal mechanism for managing the affairs of persons who lack decision-making capacity is found in the wards of court system, where a "ward" means a person who has been declared to lack capacity to manage themselves and their affairs. Under this system the personal and property affairs of the ward are managed by a committee who are appointed and supervised by the Courts, with the Courts having ultimate decision making jurisdiction. It is unfortunate that jurisdiction over the affairs of wards is still governed by a statute that is almost 150 years old and

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[270] *In bonis Corboy: Leahy v Corboy*, *supra* note 268, at 167
[271] *In re Glynn*, *supra* note 258.
[272] *Ibid* at 330.
[273] *Ibid*.

contains insultingly antiquated language, being the Lunacy Regulation (Ireland) Act 1871[274]. The Lunacy Regulation (Ireland) Act[275] provides that a person may be admitted to wardship, it must be established that the person is of unsound mind *and* incapable of managing himself or his affairs.[276] The assessment of incapacity in an application for wardship is based on medical evidence and admission to wardship involves the submission of a petition accompanied by supporting affidavits from two medical practitioners.

It is usual automatic and circular that once admitted to wardship, a ward will be found to lack legal capacity.

As law lecturer, Mary Donnelly, states in her article on the assessment of capacity:

> "It is therefore to be expected that admission to wardship would displace the requirement for a separate capacity assessment in respect of a number of business or finance related functions"[277]

The Irish Law Reform Commission has suggested that, under the current law, a ward is also deemed automatically incapable of giving consent to medical treatment.[278] As seen in *In Re a Ward of Court*, the Court will make a decision in relation to healthcare of a

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[274] The term "lunatic" is defined by section 2 of the 1871 Act as meaning "any person found by inquisition idiot, lunatic, or of unsound mind, and incapable of managing himself or his affairs." In *In the Matter of Wards of Court and In the Matter of Francis Dolan, [2007] IESC 26* , Geoghegan J described it as being "more than understandable that parents would take umbrage at the terminology" of the Lunacy Regulation (Ireland) Act 1871.

[275] As supplemented by Order 67 of the Rules of the Superior Courts (S.I. No. 15 of 1986).

[276] Section 3, Lunacy Regulation (Ireland) Act 1871. *In the Matter of Catherine Keogh*, High Court, unreported, October 15 2002,Finnegan P held that both parts of the admission requirement must be met and where an individual was incapable of handling her affairs but was not of unsound mind, she could not be admitted to wardship. However, the case law has given a special meaning to "unsound mind" in the wards of court context. In the High Court case of *In the Matter of Wards of Court and In the Matter of Francis Dolan* [2007] IESC 26 Kelly J found that the expression "person of unsound mind" meant no more than that the person was "incapable of managing his affairs." I am more inclined to the two part test. However I did not consider it relevant to the subject matter of the thesis to more fully address, the wardship procedure.

[277] Mary Donnelly, "Assessing Legal Capacity: Process and the Operation of the Functional Test" (2007) 2 Judicial Studies Institute Journal 141 at 150 [Donnelly, "Assessing Capacity"]. In *Re Walker (a Lunatic so found)* [1905] 1 Ch 160, a ward, by virtue of his legal status, was automatically deemed to be legally incapable of executing a deed.

[278] Ireland, Law Reform Commission, *Consultation Paper on Vulnerable Adults and the Law: Capacity* (Dublin: Law Reform Commission, 2005) [LRC Consultation Paper, *Capacity*] at 90.

ward on the grounds of "best interests" and this responsibility comes from the Court's *parens patriae* jurisdiction in relation to wards of court.[279] There appears to be "a level of unease" with an automatic designation of incapacity to make healthcare decisions based on admission to wardship.[280] Donnelly suggests that a ward's right to make her own decision in respect of health care should subsist where the ward is found to be capable following a separate assessment of capacity to make healthcare decisions.[281] Arguably, this capacity would then be assessed on the test set out in *Fitzpatrick*, which test is set out above at paragraph 5.1.1.

It does not appear that it would be possible, under the current system, for a ward to create an ACD following admission to wardship. It is also questionable, whether an Irish court would find that an ACD, even if made while the ward has capacity, retains applicability to a ward. In *JM v. St Vincent's Hospital and Others*[282], the Irish High Court considered an application to override an advance refusal of blood products by an unconscious woman. It was undisputed that the woman had legal capacity at the time of the refusal; however the Court did not find that the refusal was a "final" decision, and allowed the application on the grounds of best interests.[283] Interestingly, the patient in this case was not a ward but the Court approached the application under its *parens patriae* jurisdiction as the patient was "not in a condition to make a decision" and was therefore covered by the jurisdiction given to the Court under the Lunacy Regulation (Ireland) Act 1871.[284]

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[279] *In Re a Ward of Court*, supra note 14. For discussion on this case, see chapter 2.

[280] Deirdre Ahern, "Healthcare Decisions: Recognising the Decision-making Capacity of Older People to Consent to and Decline Medical Treatment" in O'Dell (ed) *Older People in Modern Ireland: Essays on Law and Policy* (Dublin: First Law, 2006), at 210.

[281] Donnelly, "Assessing Capacity", *supra* note 277 at 151.

[282] *JM v St Vincent's Hospital and Others* [2003] 1 IR 321.

[283] *Ibid* at 325.

[284] *JM v St Vincent's Hospital*, *supra* note 282 at 322; See Section 103, Lunacy Regulation (Ireland) Act 1871; It was held in *In re Birch* (1892) 29 LR Ir 274 and affirmed by the Irish Supreme Court in *In re D* [1987] IR 449 that "The parental care of the Sovereign extends over all idiots and lunatics, whether so found by legal process or not." The decision in *JM v St Vincent's Hospital and Others* that the patient came under the application of the Lunacy Regulation Act purely on the grounds of her unconsciousness is very questionable.

### 5.1.3 Capacity Under Mental Health Law

The Mental Health Act 2001 ("MHA") provides for the admission and treatment of persons suffering from mental disorders. "Mental disorder" is defined by the MHA as "mental illness, severe dementia or significant intellectual disability"[285] where:

a) "because of the illness, disability or dementia, there is a serious likelihood of the person concerned causing immediate and serious harm to himself or herself or to other persons or
b) the judgment of the person concerned is so impaired that failure to admit the person to an approved centre would be likely to lead to a serious deterioration in his or her condition or would prevent the administration of appropriate treatment that could be given only by such admission, or
c) the reception, detention and treatment of the person concerned in an approved centre would be likely to benefit or alleviate the condition of that person to a material extent."[286]

As can be seen from the above definition, the legislation has a broad application, and is not confined to mental illnesses, such as schizophrenia, but extends to dementia and significant intellectual disability.[287]

The legislation is clear that, where the MHA applies, medical treatment is to be carried out on the basis of "best interests".[288]This is provided for under section 4(1) of the MHA, which sets out that:

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[285] Section 3(2) of the MHA defines mental illness as ''a state of mind of a person which affects the person's thinking, perceiving, emotion or judgment and which seriously impairs the mental function of the person to the extent that he or she requires care or medical treatment in his or her own interest or in the interest of other persons."

[286] Section 3(1), MHA.

[287] "Significant intellectual disability" is defined by the MHA as "a state of arrested or incomplete development of mind" which includes, but is not limited to "significant impairment of intelligence and social functioning and abnormally aggressive or seriously irresponsible conduct". See Section 3(2), MHA. Notwithstanding and ancillary to this provision, the Irish courts appear to have an inherent jurisdiction to order the admission to care facilities and treatment of "vulnerable adults", which jurisdiction stems from the doctrine of necessity. See *Health Service Executive v O'B [a person of unsound mind not so found]* [2011] IEHC 73.

> "In making a decision under this Act concerning the care or treatment of a person (including a decision to make an admission order in relation to a person), the best interests of the person shall be the principal consideration with due regard being given to the interests of other persons who may be at risk of serious harm if the decision is not made."

The MHA also provides that due regard shall be given to the need to respect the right of the person to dignity, bodily integrity, privacy and autonomy.[289] However the primacy of the patient's "best interests" means that treatment can be carried out against a person's expressed wishes, which may include previously expressed wishes.[290]

Section 57 of the MHA provides for the carrying out of treatment without the consent of a patient where the "treatment is necessary to safeguard the life of the patient, to restore his or her health, to alleviate his or her condition, or to relive his or her suffering" and where the patient is incapable of giving consent by reason of their mental disorder.[291]

The application of section 57 is clearly very broad and it is highly litigated, with almost all court decisions favouring treatment in the best interests of the patient. Treatment is defined by the MHA as including "physical, psychological and other remedies relating to the care and rehabilitation of a patient under medical supervision, intended for the purposes of ameliorating a mental disorder"[292] Recent decisions of the Irish Courts have allowed for a broad reading of "treatment" under the MHA, allowing for the carrying out of the following treatment without obtaining the patients' consent: restraint and sedation

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[288] Treatment, under the provisions of the MHA, can only be carried out on persons who have been admitted to a relevant and approved treatment centre, as defined by the MHA. It does not extend to patients ordinarily and voluntarily admitted to a general hospital facility. See section 14, MHA.

[289] Section 4(3), MHA.

[290] See "HSE wins right to force ECT on patient" , The Sunday Times, see online, <www.thesundaytimes.co.uk/sto/news/ireland/article1258456.ece >.

[291] This treatment includes electro shock therapy and medication, respectively under sections 59 and 60 MHA. The exception to these provisions on treatment is psycho-surgery, meaning any surgical operation that destroys brain tissue or the functioning of brain tissue and which is performed for the purposes of ameliorating a mental disorder. This tyre of surgery can only be carried out with the written consent of the patient and the authorisation of the mental health tribunal, and only if in the best interests of the patient. See section 58, MHA.

[292] Section 2, MHA.

to facilitate the obtaining of blood samples and the administration of medication that carries a risk to the patient's white blood cell count[293]; breast cancer surgery[294] and the taking of blood samples from a minor[295]

The Irish Courts have ruled that the application of the MHA in respect of treatment must be done in a constitutional manner, and that while the role and opinions of the psychiatrists remains pivotal, the patient's choice, however conveyed, "must always be part of the balance."[296]

Where the patient is capable of giving consent, section 56 provides that that consent must be informed, and capacity to give consent is assessed on the basis of the patient "understanding the nature, purpose and likely effects of the proposed treatment." However the application of this provision is often circular, as there appears to be a presumption in the relevant jurisprudence that persons covered by the provisions of the MHA are automatically suffering from mental incapacity.[297]

It is possible that an ACD could, or perhaps should, be taken into consideration in relation to medical treatment under the MHA. The continued applicability of advance wishes is an argument that is yet to be made successfully in an Irish court, and it is arguable that not enough weight has been placed on autonomy in the area of mental health by the Irish Courts. It is debatable that both the Irish Courts and legislature are not dealing in a progressive manner with the panoply of conditions that are currently covered

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[293] *Health Service Executive v MX* [2011] IEHC 326.

[294] See "Court allows urgent breast cancer Surgery" <www.irishtimes.com/newspaper/ireland/2013/0205/1224329658074.html>.

[295] *HSE v JM & anor* [2013] IEHC 12.

[296] *MX (APUM)) v Health Service Executive & ors* [2012] IEHC 491.

[297] See *Health Service Executive v MX* [2011] IEHC 326, where MacMenamin J states, at paragraph 2 of his judgment: "But circumstances may also exist where, for example, the very nature of a mental illness clouds understanding, and where the task of decision-making for a patient becomes difficult. Then, where there is a want of capacity to make such decisions, psychiatrists have often found themselves in a position where it was they alone who were cast in the role of having to make choices in the patient's best interest, albeit, where possible, in consultation with colleagues and family members" And again at paragraph 22: "But, as has been mentioned earlier, the medical and psychiatric view is that the defendant lacks the capacity to consent; thus, by reference to s. 56(a), the court must proceed on the basis that she, as a patient, is incapable of understanding the nature, purpose and likely effects of the proposed treatment." This is very different to the treatment of mental health by the Canadian Courts, where mental illness is not conflated with incapacity. See *Starson v. Swayze*, 2003 SCC 32, [2003] 1 SCR 722.

by the MHA. This area involves a delicate and nuanced balancing of the best interests of the person with their right to autonomy, especially where the treatment concerned may possible return the patient to an autonomous state. The reasoning for this demands more focused scrutiny than can be addressed in this thesis.

### 5.1.4 A Better Test for Capacity in Relation to Medical Treatment: Assisted Decision Making (Capacity) Bill

The approach of the Irish courts to the issue of capacity appears to be that of the status approach, meaning that a decision on a person's legal capacity is based on the presence or absence of certain characteristics and it "usually involves an across-the-board assessment of a person's capacity based on disability rather than capacity in relation to the particular decision being made at a particular time."[298] This approach is particularly true in respect of cases taken under the MHA and in relation to wardship matters. It is also seen in cases like *In Bonis Corboy*, referred to above in section 5.1.1. The status approach has been criticised by the Law Reform Commission as being inequitable in relation to fluctuating capacity.[299] Furthermore, the approach does not appear to be in line with current thinking on a person's continued ability to value even where there is a diminished overall capacity.[300]

The approach recommended by the Law Reform Commission is the functional approach. This approach is issue-specific and recognises that "assessment of capacity should be narrowed to the particular decision which needs to be made".[301] The LRC recommends that legislation on capacity should contain a functional definition of capacity which focuses on the "ability to understand the nature and consequences of a decision in the

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[298] LRC Report, *Capacity*, *supra* note 256 at 26.

[299] LRC Consultation Paper, *Capacity*, *supra* note 278 at 43: "A status approach to capacity has particular potential to operate inequitably in relation to persons whose capacity fluctuates, for example, persons who have long periods of capacity alternating with shorter periods where cognitive ability is significantly impaired by an episode of mental illness."

[300] See Agnieszka Jaworska, "Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value" (1999) 28:2 Philosophy and Public Affairs 105.

[301] LRC Consultation Paper, *Capacity*, *supra* note 278 at 54.

context of available choices at the time the decision is to be made."[302] There is no obvious reason why capacity to make a healthcare decision should not be covered by the functional approach to capacity; the test appears to be consistent with the test in *Re C*, which was applied by the Court in *Fitzpatrick*.[303]

The functional approach to capacity will be given legislative footing under proposed Irish legislation, the Assisted Decision-Making (Capacity) Bill 2013, which introduces an assisted decision-making model for adults lacking in capacity.[304] The explanatory memorandum to the Bill sets out that the purpose of the legislation is:

> "to reform the law and to provide a modern statutory framework that supports decision-making by adults and enables them to retain the greatest amount of autonomy possible in situations where they lack or may shortly lack capacity."[305]

The Assisted Decision-Making Bill applies to any intervention taken against a person, whose capacity is being called into question or may shortly be called into question, including interventions taken by a healthcare professional.[306] The Bill provides that capacity is always presumed unless the contrary can be shown in accordance with the provisions of the Bill.[307] The functional approach to the assessment of capacity is set out in Section 3 of the Assisted Decision-Making Bill which provides that "a person's capacity shall be assessed on the basis of his or her ability to understand the nature and consequences of a decision to be made by him or her in the context of the available choices at the time the decision is made." This new legislation will apply a more flexible approach to the assessment of capacity. Section 3(4) provides that a person is regarded as having the capacity to make a decision even if he or she is able to retain the information relevant to the decision for a short time only. The Bill further provides that a person shall

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[302] LRC Report, *Capacity*, *supra* note 256 at 51.

[303] *Re C*, *supra* note 160; *Fitzpatrick v FK*, *supra* note 4.

[304] Ireland, Assisted Decision-Making (Capacity) Bill 2013, Bill 83/2013 [Assisted Decision-Making Bill 2013].

[305] Explanatory Memorandum, Assisted Decision-Making (Capacity) Bill 2013,<//www.oireachtas.ie/documents/bills28/bills/2013/8313/b8313d.pdf>, at 1.

[306] Section 2, Assisted Decision-Making Bill 2013.

[307] Section 8 (2), Assisted Decision-Making 2013.

not be considered as unable to make a decision merely by reason of making, having made, or being likely to make, an unwise decision.[308]

The test used by the Court in *Fitzpatrick* appears to be given a legislative footing under section 3(2), which clarifies that a person lacks the capacity to make a decision if he or she is unable:

> "(a) to understand the information relevant to the decision,[309]
>
> (b) to retain that information,
>
> (c) to use or weigh that information as part of the process of making the decision, or
>
> (d) to communicate his or her decision (whether by talking, writing, using sign language, assisted technology, or any other means) or, if the implementation of the decision requires the act of a third party, to communicate by any means with that third party."

This assessment of capacity does appear to be is in line with the approach taken in relation to capacity to refuse medical treatment,[310] and arguably, is transferable to the question of capacity to make an ACD. However, if the requirements of Section 3(2)(a) , (b) and (c) are treated as separate criteria and not given a cumulative interpretation, the test required for capacity in this Bill appears to be narrower than the assessment applied by the Court in *Fitzpatrick*.[311] Whether this is the case or not depends on the application of the Assisted Decision-Making Bill.

This legislation is currently working its way through the Irish legislature and would only apply to ACD made following the commencement of the legislation, when and if the Bill

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[308] Section 8 (4) Assisted Decision-Making Bill 2013.

[309] Section 3(5), Assisted Decision-Making 2013 provides that information relevant to a decision includes information about the reasonably foreseeable consequences of the available choices and of failing to make a decision.

[310] *Fitzpatrick v FK*, *supra* note 4.

[311] *Ibid*.

is enacted. Until then, the standard to be met in relation to the assessment of capacity is set out in the precedent from the Irish Courts.

### 5.1.5 Conclusions in Relation to the Capacity Requirement

For a valid ACD, a person will have to be functionally capable at the time of making the ACD. It appears that this will require the person to be able to understand the nature and consequences of a decision in the context of available choices at the time the decision is made. Guidance as to what is exactly mean by this in relation to healthcare decisions can be drawn from the application of the *Re C* test by Laffoy J in *Fitzpatrick v FK*.[312]

As there is no legislation on the making of ACD, there is no requirement for the holder of the ACD to prove capacity at the time of making as capacity must be presumed. However, this presumption can be overturned. There may be an argument that additional documents such as a statuary declaration by physician validating the person's mental capacity may be helpful evidence should the ACD's validity be questioned. Further, the assessment of capacity in relation to consent to medical treatment remains heavily a "matter of clinical judgment"[313] This is especially seen in the reliance of judges in Irish case law on capacity on the physician's assessment of capacity particularly in relation to cases under the MHA.[314] Given this, it may be advised that an individual making an ACD obtain evidence of their capacity.

## 5.2 Informed Choice

I will now turn briefly to the question of whether the decision to make an ACD must be informed.

There is a duty on a physician to ensure that consent to medical treatment is informed and this duty is based in the right to autonomy. The Irish Medical Council's current Guide to Ethical Conduct and Behaviour states:

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[312] *Fitzpatrick v FK*, *supra* note 4. See discussion at section 5.1.1.

[313] Beauchamp & Childress, *supra* note 106 at 115.

[314] See *MX (APUM) v Health Service Executive & ors* [2012] IEHC 491.

> "As part of the informed consent process, patients must receive sufficient information, in a way that they can understand to enable them to exercise their right to make informed decisions about their care this refers to the disclosure of all significant risks or substantial risks of grave adverse consequences."[315]

The requirement for informed consent is clear in relation to consent to treatment. This is not the case in relation to the use of ACD, which is why I will refer to "informed decision making" or "informed choice" in relation to the use of ACD. The English High Court has rejected the argument that an absence of informed choice would nullify a refusal of treatment. In *Re T,* Donaldson MR stated:

> "There is indeed a duty on the part of doctors to give the patient appropriately full information as to the nature of the treatment 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."[316]

Other courts have recognised that there may be a principle of informed refusal. In the Canadian case of *Malette v Shulman*, the defendant physician argued that he was not obliged to follow an ACD where he was not certain that the treatment refusal set out in the ACD was the informed choice of the ACD holder.[317] The Court rejected this argument on the basis of a lack of evidence for the physician's concerns.[318]

A requirement of informed decision making may encroach on a certain interpretation of autonomy. Another way of approaching this issue is to see it as a waiver of the right to be informed, as part of the right to autonomy.[319] The Irish Council for Bioethics recognises

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[315] Irish Medical Council, Guide to Professional Conduct and Ethics for Registered Medical Practitioners, 7th edition (Irish Medical Council, 2009) at paragraph 35.2.

[316] *Re T*, *supra* note 149 at 663.

[317] *Malette v Shulman*, *supra* note 104 . I have more fully address this decision in section 4.1.6.

[318] *Ibid* at paragraph 44.

[319] Margaret Somerville, "Labels versus Contents: Variance between Philosophy, Psychiatry and Law in Concepts Governing Decision-Making", (1993) 39 McGill LJ 179 at 189.

that "(c)ertain individuals may not wish to take counsel on the matter and they might not be able to avail of such advice for personal, financial or other reasons."[320]

The Irish Council of Bioethics, in their report on ACD, also opines that the validity of an ACD is not affected by the absence of an informed choice:

> "However, given that a competent individual can forgo receiving any information yet still consent to or refuse medical treatment in contemporary situations, the perceived lack of information about future medical eventualities when drafting an advance directive may not be a sufficient reason to doubt the validity of a directive."[321]

Where there is legislation on ACD, it usually does not make the obtaining of advice or informed decision making a prerequisite to a valid ACD, for example the Scottish Mental Health (Care and Treatment) Act 2005.[322]

Despite the foregoing concerns about the requirement of informed choice, I would argue that the test for capacity in relation to consent to medical treatment, set out by Laffoy J in *Fitzpatrick v FK* envisages an exchange of information. This test for capacity is measured in reference to the patient's response to the relevant treatment information, being treatment that is medically indicated.[323] The difficulty in the application of this requirement to the making of an ACD is that there may be no "medically indicated treatment" at the time of the making of the ACD. An individual may prefer not to specify or may not be in a position to specify what treatment will be relevant in the scenarios they wish to avoid, or the treatment that they wish to have, when making their ACD.

This requirement, if it is extant, will be easier met in some case than others, for example in the case of an individual who does not want to receive blood products, it would be more straightforward for that person to receive information in relation to the relevant

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[320] Irish Council for Bioethics, *Advanced Healthcare Directives supra* note 8 at 23.
[321] *Ibid*.
[322] Section 275, Scotland, Mental Health (Care and Treatment) (Scotland) Act 2003.
[323] *Fitzpatrick v FK*, *supra* note 4 at 40-42.

treatment alternatives to blood products and to envisage the consequences of not receiving blood products where it is the medically indicated treatment. Alternatively, for someone who wishes not to be "kept alive artificially" following catastrophic brain injury,[324] it may be an onerous task to address all reasonably possible treatment options.

Following on from this point, it was held *In Re a Ward of Court* that a competent person may refuse treatment against medical advice for whatever reason, and that this right to refuse is a facet of the principle of autonomy.[325] I would suggest that it follows that it is an expression of that very autonomy to make an ACD without the requirement for an informed choice. As such, it may be the case that the issue of treatment information and informed choice only arises where the capacity of individual, at the time of the making of the ACD and its application, is in question. If this is the case, then meeting the standards of informed choice is more a recommendation than a prerequisite to a lawful ACD.

There is an argument to be made that autonomy is best served by an informed choice.[326] Some commentators are of the opinion that if ACDs are to truly serve their purpose they must be executed with the help and explanation of physician and other health care professionals and to do otherwise is ethically indefensible.[327]

I am not going to take such a stance in this thesis however I would strongly recommend that an individual's decision to make an ACD is an informed decision. It is likely to be the case that a more informed decision in relation to ACD creation will result in a more clear (and more robust) ACD in practice. The importance of informed choice to the clarity of an ACD is reflected in the decision of the English High Court in *W Healthcare NHS Trust v H*, where the Court overturned evidence of the previously expressed wishes of the patient relating to the removal of life support, on the grounds of the absence of

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[324] For example, if there were similar facts as in the case of *Re Ward of Court*, *supra* note 14.

[325] *In Re a Ward of Court*, *supra* note 14.

[326] I am using the understanding of autonomy as set out by Beauchamp & Childress, supra note 106, and discussed in Chapter 3.

[327] Erich Loewry, "Ethical Considerations in Draft and Implementing Advance Directives" (1998) 158 Arch Intern Med 321 at 323.

clarity. In its judgment, the Court focused on the lack of evidence of informed choice in reaching its conclusion, stating:

> "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."[328]

The informed nature of a decision is also reflected in the clarity of the expression of the ACD, and I will discuss this point further in section 5.4.4.

## 5.3 Unlawful or Invalid Requests in an ACD

Even if capacity is present, the measures requested under an ACD cannot be unlawful. The obvious area where this would be the case in Irish law is in respect of assisted suicide or euthanasia. However it is possible that a request for medically futile treatment would equally be invalid. I will address both points, and the issue of minors in the following sections.

### 5.3.1 Assisted Suicide / Euthanasia

Both assisted suicide and euthanasia are currently illegal under Irish law.

Euthanasia refers to the actions of a third party, usually a doctor, to deliberately end the life of an individual; euthanasia is prohibited under laws against homicide.[329] Assisted suicide is where an individual takes their own life based on guidance, information and/or

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[328] *W Healthcare NHS Trust v H*, *supra* note 5 at 839.

[329] There is no specific statutory interpretation or definition of euthanasia under Irish law. Euthanasia was defined by the Supreme Court, in *In Re a Ward of Court*, supra note 14 at 130, as relating to "the termination of life by a positive act". It therefore comes under the definition of homicide found in section 4, Ireland, Criminal Justice Act 1964.

medication given to them by a third party. Assisted suicide is currently prohibited under section 2(2) of the Criminal Law (Suicide) Act, 1993, which provides:

> "(2) A person who aids, abets, counsels or procures the suicide of another, or an attempt by another to commit suicide, shall be guilty of an offence and shall be liable on conviction on indictment to imprisonment for a term not exceeding fourteen years."

The constitutionality of the prohibition in relation to assisted suicide has been most recently explored by the Irish High and Supreme Courts in the Case of *Fleming v Ireland.*[330]As clarified by the Court in *Fleming*, "(w)hile suicide has ceased to be a crime, the fact that it has so ceased does not establish a constitutional right."[331] As set out in Chapter 2, it was emphatically held by the Supreme Court that there is *no* express or implied constitutional right "either to commit suicide, or to arrange for the termination of one's life at a time of one's choosing."[332]

The *Fleming* decision in relation to the constitutionality of the prohibition on assisted suicide follows decisions in other common law jurisdictions, such as Canada and the United Kingdom.[333] The comparison with Canadian jurisprudence is particularly apt as the language of the Canadian prohibition, being Section 241(b) of the Canadian Criminal Code is very similar to the Irish provision. Section 241(b) states:

> "Everyone who (*a*) counsels a person to commit suicide, or (*b*) aids or abets a person to commit suicide, whether suicide ensues or not, is guilty of an indictable offence and liable to imprisonment for a term not exceeding fourteen years."

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[330] *Fleming v Ireland* (High Court) *supra* note 25; *Fleming v Ireland* (Supreme Court), *supra* note 25.

[331] *Fleming v Ireland* (Supreme Court), *supra* note 25 at paragraphs 113-114.

[332] *Ibid* at paragraph 9.

[333] In the United Kingdom, assisted suicide is prohibited under s 219 of the Suicide Act 1961. In *R (Pretty) v. DPP* [2001] UKHL 61, the House of Lords found that the prohibition did not breach the European Convention of Human Rights.

The constitutionality of this provision was affirmed by a majority of the Supreme Court of Canada in the case of *Rodriguez v. British Columbia*,[334] which decision was cited by the court in *Fleming*.[335] The Court in *Fleming* noted that the actual language of Section 7 of the Canadian Charter of Rights, which was relied on by the applicant in *Rodriguez*, is very similar to that of Article 40.3.2, the relevant Irish constitutional provision. [336] Section 7 of the Charter provides:

> "Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice."

The Canadian Supreme Court upheld Section 241(b), but on slightly difference grounds from the Irish decision. The Canadian Court stated that the prohibition might infringe section 7 of the Charter; however, it was not unconstitutional as it was not contrary to the principles of fundamental justice. In *Rodriguez,* Sopinka J pointed out that the prohibition had "a clearly pressing and substantial legislative objective grounded in the respect for and the desire to protect human life, a fundamental Charter value."[337]

The differences between the reasoning of the judgments of the Canadian and Irish courts highlights that this issue is one which is very specific to the culture and ethos of the particular jurisdiction, notwithstanding the similarities of the positive law.[338]

The Courts in Ireland and Canada have pursued similar treatment of the distinction between assisted suicide and the withdrawal or withholding of treatment, the latter being

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[334] *Rodriguez v. British Columbia* [1993] 3 SCR 519.

[335] *Fleming v Ireland* (High Court*) supra* note 25 at paragraphs 85-86; *Fleming v Ireland* (Supreme Court), *supra* note 25 at paragraphs 49-58.

[336] *Fleming v Ireland* (High Court*) supra* note 25 at paragraph 85.

[337] The issue of assisted suicide and the decision in *Rodriguez* will most likely be revisited by the Canadian Supreme Court if the case of *Carter v Canada (Attorney General)* 2013 BCCA 435 is appealed from the decision of the British Columbia Court of Appeal to the Supreme Court.

[338] This is reflected in the jurisprudence of the European Court of Human Rights on the application of the European Convention on Human Rights (ECHR) in this matter, which has held that member states are entitled to regulate activities which are detrimental to the life and safety of individuals, and that blanket bans on assisted suicide are permissible under the ECHR. See *Pretty v. United Kingdom*, (Application No. 2346/02).

permissible in both jurisdictions under the principle of autonomy.[339] This was addressed by Sopinka J in *Rodriguez* as follows:

> "The distinction between withdrawing treatment upon a patient's request…and assisted suicide…has been criticized as resting on a legal fiction - that is, the distinction between active and passive forms of treatment. The criticism is based on the fact that the withdrawal of life supportive measures is done with the knowledge that death will ensue, just as is assisting suicide, and that death does in fact ensue as a result of the action taken […]

Whether or not one agrees that the active vs. passive distinction is maintainable, however, the fact remains that under our common law, the physician has no choice but to accept the patient's instructions to discontinue treatment. […] The doctor is therefore not required to make a choice which will result in the patient's death as he would be if he chose to assist a suicide or to perform active euthanasia."

Despite the findings on the absence of a constitutional right in respect of suicide, the *Fleming* judgment leaves open the possibly for the removal of the prohibition against assisted suicide but only through action by the legislature. The Irish Supreme Court stated in its judgment:

"Nothing in this judgment should be taken as necessarily implying that it would not be open to the State, in the event that the Oireachtas were satisfied that measures with appropriate safeguards could be introduced, to legislate to deal with a case such as that of the appellant. If such legislation was introduced it would be for the courts to determine whether the balancing by the Oireachtas of any legitimate concerns was within the boundaries of what was constitutionally permissible. Any such consideration would, necessarily, have to pay appropriate regard to the assessment made by the Oireachtas both of any competing interests and the practicability of any measures thus introduced."[340]

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[339] See *In Re Ward of Court*, *supra* note 14.

[340] *Fleming v Ireland* (Supreme Court), *supra* note 25 at paragraph 108.

As the law currently stands, it is would not be lawful for a measure to be requested in an ACD if that measure would amount to assisted suicide or euthanasia. This is an extremely serious matter as there is the real potential for criminal prosecution against any person carrying out assisted suicide or euthanasia in Ireland. For the sake of adding some clarity to what will amount to such measures, in the case of *Fleming*, the applicant was seeking assistance in death through self administered gas though a face mask or by a lethal injection.[341]

Finally on this issue and importantly for the purposes of making a lawful ACD, withdrawal or withholding of treatment is not euthanasia, as was found in *Re Ward of Court*.[342]

### 5.3.2 Life Sustaining or Medically Futile Treatment

I have assumed that most ACDs stipulate a refusal, withdrawal or withholding of treatment but it is possible that an individual would like to ensure that they would not be *removed* from life sustaining treatment, where that treatment is considered medically futile, that is where there is no medical benefit.[343] The Courts in Ireland have yet to address the issue of whether there is a right to insist on life sustaining measures or indeed whether there is a right to health care. *In Re a Ward of Court*[344] is precedent that the removal of life sustaining measures may be in the best interests of a patient.[345] However, the constitutional protection for the right to life may provide an argument that there is a right to life sustaining treatment, but there may not be a right to what is considered medically futile treatment.

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[341] *Fleming v Ireland* (Supreme Court), *supra* note 25 at paragraph 17.

[342] See *In Re a Ward of Court*, *supra* note 14.

[343] Medical futility relates to what is considered to be within the standard of care of a physician to provide, below which standard the physician could be held as negligent. The Report of the Canadian Special Senate Committee, *Of Life and Death*: *Report of the Special Senate Committee on Euthanasia and Assisted Suicide*" (1995), at 45, defines futile treatment as "treatment that in the opinion of the health care team will be completely ineffective."

[344] In *Re a Ward of Court*, *supra* note 14.

[345] See the discussion of *In Re a Ward of Court*, supra note 14, in section 2.2.

Courts in other common law jurisdiction, like Canada, the United Kingdom and the United States of America have been reluctant to require a doctor to provide or continue life support treatment that was found to be outside the professional medical standard of care. The approach of the English courts is that where the patient is not in unable to give or withhold consent, it is lawful to withdraw life support where the continuation of life support is not in the patient's best interests.[346] In *Airedale NHS Trust v Bland*,[347] the House of Lords held that health care providers would not be criminally or civilly liable for withdrawing treatment from a patient in a persistent vegetative state, where, in the physicians' view, there was no possibility that he would regain consciousness and where continuing life support was not in the patient's best interests. The decision in *Bland* was cited with approval by the Irish Supreme Court in *In Re a Ward of Court*.[348]

This issue of withdrawal from life sustaining treatment was most recently addressed by the Supreme Court of Canada in *Cuthbertson v Rasouli*[349], which concerned an application to remove an unconscious patient from life support where the physicians were of the opinion that the life support was not providing any medical benefit to the patient.[350] There was no ACD, but the patient's wife, being his substitute decision maker under Ontario statute law (the Health Care Consent Act (HCCA)) objected to the removal.[351] The scheme of the HCCA ensures that when treatment is proposed, doctors, substitute decision-makers and the Board, are all bound by the patient's known wishes, if clear and applicable. The Supreme Court found that the HCCA precluded the physician from acting unilaterally in withdrawing lifesaving treatment and therefore did not have to address whether the patient had a common law right to the life sustaining treatment where

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[346] In *Airedale NHS Trust v Bland*, [1993] AC 789, Goff LJ stated, at p. 868, that in such cases, the Court's task was not to determine "whether it is in the best interests of the patient that he should die. The question is whether it is in the best interests of the patient that his life should be prolonged by the continuance of this form of medical treatment or care."

[347] *Ibid*.

[348] *Re a Ward of Court*, *supra* note 14.

[349] *Cuthbertson v Rasouli* 2013 SCC 53 [*Rasouli*].

[350] Mr Rasouli is being kept alive by mechanical ventilation, connected to a tube surgically inserted into his trachea, and artificial nutrition and hydration, delivered through a tube inserted into his stomach. *Rasouli*, *supra* note 349, at paragraph 5. There is an argument that the treatment in Rasouli was not medically futile as it is keeping Mr Rasouli alive.

[351] Health Care Consent Act, 1996, SO 1996, c 2, Sch A.

physicians were of the opinion that it was medically futile. While there was no ACD or prior expressed wishes, the Court noted that the provisions of the HCCA require that the prior wishes of the patient be taken into consideration but such wishes are only binding if they are applicable to the patient's current circumstances. If the prior wishes were not applicable, treatment should be decided on the basis of best interests.[352] In *obiter*, the Court stated:

> "The question is whether, when the wish was expressed, the patient intended its application in the circumstances that the patient now faces: see *Conway*, at para. 33; *Scardoni*, at para. 74. Changes in the patient's condition, prognosis, and treatment options may all bear on the applicability of a prior wish: *Conway*, at paras. 37-38."[353]

The dissenting opinion of the Court, per Abella and Karakatsanis JJ, found that there was no common law right to insist on medically futile treatment and that patient consent was not required to withdraw life-sustaining treatment in such circumstances.[354] In relation to this point, Karakatsanis J stated:

> "When the issue is the withdrawal of treatment that is no longer medically effective or is even harmful, a patient's choice alone is not an appropriate paradigm. A patient's autonomy must be balanced against broader interests, including the nature of her condition, the implications of continuing the treatment, the professional obligations of her physicians, and the impact on the broader health care system."[355]

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[352] *Rasouli*, *supra* note 349 at paragraph 87. It should be noted that in *Rasouli*, McLaughlin CJ stated that she was unable to "locate any case in which there was a prior expressed wish opposing withdrawal of life support that was held to be applicable and therefore binding in the circumstances." See *Rasouli, supra* note 349 at paragraph 83.

[353] *Ibid* at paragraph 82. See also *Conway v. Jacques* (2002), 59 OR (3d) 737, where the Ontario Appeal Court noted, at paragraph 31, that: "...prior capable wishes are not to be applied mechanically or literally without regard to relevant changes in circumstances. Even wishes expressed in categorical or absolute terms must be interpreted in light of the circumstances prevailing at the time the wish was expressed."

[354] *Rasouli*, *supra* note 349 at paragraph 186.

[355] *Ibid* at paragraph 136.

It is fair to say that it appears that, where it applies, the HCCA has built upon the common law rights in relation to consent to treatment. The Courts in the United States of America have also declined to address the issue of whether a patient has the right to insist on life support.[356] Some States in the USA permit requests for life sustaining treatments in an ACD.[357] Other states, however, have enacted statutes that allow for the unilateral withdrawal or withholding of life sustaining treatment by health care providers when it is deemed medically inappropriate.[358]

As there are no Irish legislative provisions or precedent providing for a right to medically futile treatment, I suggest that an ACD providing for such measures, while not *prima facie* unlawful, would be open to challenge.[359]

### 5.3.3 Minors

Irish law in relation to the right to consent to treatment envisages that right being exercised by an "adult".[360] This raises the question as to when the wishes of a minor, that is a person under the age of 18, should be taken into consideration.

It is usually the case that minors do not have legal capacity to execute certain important documents, such a will,[361] nor do they have legal capacity to consent to certain acts, such as marriage[362] or to serve on a jury[363]. In relation to medical treatment, section 23 of the Non-Fatal Offences against the Person Act 1997[364] provides that minors over the age of

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[356] *In Re The Conservatorship of Helga M. Wanglie*, No. PX-91-283 (Minn Dist Ct (Prob Ct Div) 1991.

[357] For example, Arizona, Idaho, Indiana, Kentucky, Maryland, Minnesota, North Dakota, Oregon, Pennsylvania, South Dakota.

[358] For example, New Mexico's Uniform Health Care Decisions Act provides, at section 24-7A-7-F, that "A health-care provider or health-care institution may decline to comply with an individual instruction or health-care decision that requires medically ineffective health care or health care contrary to generally accepted health-care standards applicable to the health-care provider or health-care institution."

[359] This does not mean that an ACD cannot request treatment directed at minimising distress in the dying process (that is palliative care) as it clearly would fall below a physician's standard of care to fail to treat pain and distress.

[360] See *In Re a Ward of Court*, *supra* note 14.

[361] Section 77, Ireland, Succession Act, 1965.

[362] Section 1, Ireland, Marriages Act, 1972.

[363] Sections 6 and 31, Ireland, Juries Act, 1976.

[364] Ireland, Non-Fatal Offences against the Person Act, 1997.

16 can give effective consent to medical treatment. This does not mean that the wishes of a minor under 16 should not be treated with respect, and the Irish courts agree on this point.[365]

There is an argument that the English concept of the "*Gillick* competent minor" is applicable in Irish law. This concept arose in the case of *Gillick v West Norfolk and Wisbech Area Health Authority*[366], in which the Court was of the view that the relevant factor was not the age of the individual but rather the ability to understand fully what was proposed. The concept has neither been expressly dismissed nor accepted by an Irish court. However, it seems to be in line with the concept of "functional capacity" proposed under the Assisted Decision-Making (Capacity) Bill 2013, discussed above in section 5.1.4. This approach also appears to have been applied by the Irish court in the recent case of *Health Service Executive v JM & anor*,[367] where MacMenamnin J stated:

> "In expressing the view that X.Y. lacks capacity to refuse to provide a blood sample which is required, I am conscious that capacity can fluctuate. I am not to be taken as being of the view that there are no decisions of a medical nature which X.Y. would not have the capacity to take. Neither, am I laying down any general principle that young people aged 15 going on 16 should always be regarded as lacking capacity. The views are specific to this fifteen year old's capacity to refuse to allow a blood sample to be taken."[368]

It appears that the formalised wishes of a minor in relation to medical treatment should be taken into consideration but cannot have the same binding effect as those of a competent adult. Any request by a minor for the removal of life sustaining treatment would best be reviewed by a court. It is also highly questionable whether an ACD can be lawfully executed by a minor, or that it would continue to have effect once that person attains adulthood.

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[365] *Health Service Executive v JM & anor*, *supra* note 282 at paragraph 23.
[366] *Gillick v West Norfolk and Wisbech Area Health* Authority [1986] AC 112.
[367] *Health Service Executive v JM & anor* [2013] IEHC 12.
[368] *Ibid* at paragraph 24.

## 5.4 What Form Should an ACD Take?

As I have explained in the introduction to this thesis, there are no Irish legislative provisions setting out the formalities required for an ACD. Some commentators on this issue refer to ACD as "living wills" and this gives the impression that testamentary provisions would apply to the making of such documents.[369] I believe this term is misleading and it is doubtful that that the Irish testamentary provisions apply in the context of healthcare instructions.[370] This position was discussed in the context of the English provisions by Munby J in *HE v A Hospital NHS Trust* who held:

> "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."[371]

It is likely that this would also apply in an Irish context and that an informally drafted document setting out an ACD should be respected. This may not provide comfort to individuals who feel that such an important document should have more regulated and formal parameters. The only option, in an Irish context, for a more "legalised" approach to healthcare instructions is that of the enduring power of attorney. The proposed Assisted Decision Making (Capacity) Bill 2013[372] aims to introduce some more measures to assist individuals in anticipation of a loss of capacity. I will discuss both options below.

### 5.4.1 Enduring Powers of Attorney

A power of attorney is an instrument signed by or by direction of a person (the "donor"), giving another person (the "donee") "the power to act on behalf of the donor in

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[369] See, for example, Liz Campbell, "The Case for Living Wills in Ireland" (2006) 12:1 Medico-Legal Journal of Ireland 2,

[370] Ireland, Succession Act, 1965.

[371] *HE v A Hospital NHS Trust* [2003] 2 FLR 408 at paragraph 35.

[372] See section 5.1.4.

accordance with the terms of the instrument".[373] The execution and drafting of these documents is regulated in Ireland by the provision of the Powers of Attorney Act 1996. A power of attorney can be created that would remain valid during any subsequent mental incapacity of the donor, this is known as an enduring power of attorney. The formal Irish guidelines for the creation of a valid enduring power of attorney are provided for under the Enduring Power of Attorney Regulations 1996.[374] In order to create a valid enduring power of attorney, the donor must have the mental capacity to understand the effect of creating the power at the time of its creation.[375]

Decisions made under an enduring power of attorney should be made "in the best interests" of the donor.[376] In deciding what is in the best interests of the donor, regard should be had to "the past and present wishes and feelings of the donor".[377] It is also possible for the donor to name a person to be consulted in respect of personal care decisions.[378]

One flaw of the use of enduring power of attorney in respect of health care decisions is that while the legislation provides for the making of "personal care" decisions, the legislative definition of such a decision does not expressly include medical treatment.[379] However the Assisted Decision Making (Capacity) Bill 2013, discussed directly below, will expand the scope of the enduring power of attorney to include health care decisions.[380] As currently drafted, the Bill will not extend the use of enduring power of attorney to decisions relating to the refusal of life sustaining treatment.[381]

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[373] Section 2, Powers of Attorney Act 1996.

[374] Enduring Powers of Attorney Regulations, SI 196/1996 and the Enduring Powers of Attorney (Personal Care Decisions) Regulations, 1996, S.I. No. 287/1996.

[375] Part D, Second Schedule, Enduring Powers of Attorney Regulations, SI 196/1996. The opinion on capacity must be validated by a registered medial practitioner. See Part E, Second Schedule, Enduring Powers of Attorney Regulations, SI 196/1996.

[376] Section 7, Powers of Attorney Act 1996.

[377] Section 6(7)(a), Powers of Attorney Act 1996.

[378] Section 6 (7)(b)(iii)(I), Powers of Attorney Act 1996.

[379] Section 4, Powers of Attorney Act 1996.

[380] Section 40(2), Assisted Decision-Making Bill.

[381] Section 41(2)(b), Assisted Decision-Making Bill.

### 5.4.2 Assisted Decision Making

For those who already lack the capacity to execute an enduring power of attorney or otherwise create an ACD, the measures that will be brought in by the Assisted Decision-Making Bill 2013 might be of assistance.

The Assisted Decision-Making Bill 2013 will establish a statutory framework to enable persons, who consider that their capacity is in question, or may shortly be in question (the "appointer")[382] to formally appoint a decision making assistant or a co-decision maker. A decision making assistant is appointed to *assist* the appointer in making decisions.[383] A co-decision maker is appointed to make decisions *jointly* with the appointer.[384]

Both types of appointment relate to decisions concerning the appointer's personal welfare, property and affairs; personal welfare includes the granting or refusing of consent to the carrying out or continuation of medical treatment.[385]

Under the Bill, the decision making assistant or co-decision maker does not have the power to substitute their decision for that of the appointer but instead has the function to advise the appointer, to ascertain their will and preferences, and to assist the appointer to make and communicate a relevant decision.[386] The type of assisted decision-making provided for by the Assisted Decision-Making Bill 2013 means that any "decision" made remains substantially a decision of the appointer.

The Assisted Decision-Making Bill 2013 provides that the Irish Minister for Heath may make regulations requiring a co-decision maker or decision making assistant to formally acknowledge that they understand their duties under the Bill.[387]

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[382] Section 18, Assisted Decision-Making Bill.

[383] Section 10, Assisted Decision-Making Bill.

[384] Section 12, Assisted Decision-Making Bill. Under Section 17 (3)(a), Assisted Decision-Making Bill , a co-decision making agreement must be approved by court order.

[385] Section 25, Assisted Decision-Making Bill.

[386] Section 11 and Section 21, Assisted Decision-Making Bill.

[387] Section 10(3)(d)(ii) and Section 18 (4)(d)(ii), Assisted Decision-Making Bill.

Finally, this new Bill will requires that interventions in respect of person whose capacity is in question, including health care interventions, must take into account "the beliefs and values of the relevant person in particular those expressed in writing".[388] While significant for the use of ACDs, this provision does not put an ACD on the same level as a contemporaneously and competently made health care decision as physicians only have to take them "into account".

### 5.4.3 Voluntariness

For an ACD to be an autonomous decision, it must be a voluntary decision. This does not mean that it must be a decision made in a relational vacuum. The reality of medical treatment decisions is that they are usually made with other family members or friends; this is recognised by the current thinking on autonomy as relational, as set out in Chapter 2. However, the network surrounding the individual making this type of decision may require scrutiny, as depending on the circumstances, it may impede the voluntariness of the decision.

In Irish courts, the review of the voluntariness of a refusal of medical treatment has been treated as a part of the assessment of capacity. In *Fitzpatrick v FK*, Laffoy J stated that:

> "That a decision to refuse life-saving treatment must represent the patient's independent decision and that a doctor or a court evaluating capacity must be satisfied that the patient's will was not overborne in such a way that the refusal will not have represented "a true decision" is beyond question."[389]

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[388] Section 8(7)(c)(i), Assisted Decision-Making Bill.

[389] *Fitzpatrick v FK*, *supra* note 4at 38. In this case, the Court ruled that no issue arose that Ms K.'s decision to refuse a blood transfusion was induced by undue influence, because there was no allegation of undue influence in the pleadings. The Court did pronounce on the potential for such influence borne out of an economic dependence and stated: "I think it is fair to record that while that Ms. K was cross-examined in relation to her perceived dependence at the time on members of the Jehovah's Witness faith in this jurisdiction, I am satisfied that one could not conclude on the evidence that her decision was motivated by fear of economic deprivation... I am satisfied that the practices and sanctions of the Jehovah's Witness religion were not, and could not properly have been, in issue in the evaluation of the quality of Ms. K's refusal on 21st September, 2006, either in the hospital or on the ex parte application." See *Fitzpatrick v FK*, *supra* note 4 at 39.

In that case, the Court opined that a decision to execute an ACD motivated by peer pressure, or fear of social or economic deprivation might not be voluntary.[390] However, this did not arise in the circumstances of this case and so all comments of the Court on voluntariness are *obiter*.

The Irish courts have not had an opportunity to set out a test for voluntariness in relation to the consent to or refusal of medical treatments. Of some assistance on this point is the English case of *Re T*, where Lord Donaldson MR, stated as follows:

> "A special problem arises if at the time the decision is made the patient has been subjected to the influence of some third party. This is by no means to say that the patient is not entitled to receive and indeed invite advice and assistance from others in reaching a decision, particularly from members of the family. But the doctors have to consider whether the decision is really that of the patient... The real question in each such case is, does the patient really mean what he says or is he merely saying it for a quiet life, to satisfy someone else or because the advice and persuasion to which he has been subjected is such that he can no longer think and decide for himself? In other words, is it a decision expressed in form only, not in reality?"[391]

Donaldson MR set out two aspects to be considered in relation to the effect of external influences on a medical decision: the strength of the will of the patient and the relationship of the "influencer" to the patient.[392] While not indicative of overbearing influence, a court might have regard to evidence of such aspects in assessing voluntariness. In the same case, Staughton LJ, added that for a "refusal of consent to be less than a true consent or refusal, there must be such a degree of external influence as to

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[390] *Fitzpatrick v FK*, *supra* note 4 at 39.
[391] *Re T*, *supra* note 149 at 662.
[392] *Ibid*.

persuade the patient to depart from her own wishes, to an extent that the law regards it as undue."[393]

I suggest that an Irish court should apply a similar method of questioning the voluntariness of an ACD. I would also suggest that the review of voluntariness take place outside the assessment of capacity given the serious effects of a finding of incapacity on a person. It is possible that influence can be exerted in a manner that does not affect the capacity of the person but instead prevents a capable person from exercising their autonomy.

### 5.4.4 Clarity of the ACD

Under Irish constitutional law, where there is a waiver of a constitutional right such as the right to life, in this context being the right to have one's life maintained through medical treatment, the waiver must be clear and unambiguous. The test for a valid consent to waiver of a constitutional right was set out by the Irish Supreme Court in the case of *G v An Bord Uchtála* as follows:

> "I am satisfied that, having regard to the natural rights of the mother, the proper construction of the [statutory] provision … is that the consent, if given, must be such as to amount to a fully informed, free and willing surrender or abandonment of these rights. However, I am also of the opinion that such a surrender or abandonment may be established by her conduct when it is such to warrant the clear and unambiguous inference that such was her fully informed, free and willing intention. In my view, a consent motivated by fear, stress or anxiety, or a

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[393] *Re T*, *supra* note 149 at 669. The examination of influence in the context of medical treatment is not the same as that in relation to financial transactions, as in the former, the stronger party will not necessarily gain commercially from the influence. This was addressed by the court in *Re T*, *supra* note 149, at 669, where Staughton LJ stated: "The cases on undue influence in the law of property and contract are not, in my opinion, applicable to the different context of consent to medical or surgical treatment. The wife who guarantees her husband's debts, or the widower who leaves all his property to his housekeeper, are not in the same situation as a patient faced with the need for medical treatment.'; See also Cameron Stewart & Andrew Lynch, "Undue Influence, Consent and Medical Treatment" (2003) 96 JRSM 598.

> consent or conduct which is dictated by poverty or other deprivation does not constitute a valid consent."[394]

Therefore, an ACD with provisions amounting to a waiver of the right to life, for example the withdrawal or withholding of life saving treatment, must be clear and unambiguous. This was specifically addressed in relation to medical treatment, by the Supreme Court of Ireland in *In re a Ward of Court*, where the Court required clear and convincing proof of all relevant matters in coming to its decision in relation to the lawfulness of the withdrawal of treatment.[395]

This approach was most recently followed by the Irish High Court in *Fitzpatrick*, where, in relation of the waiver of the patient's right to life, Laffoy J stated:

> "It seems to me that the appropriate threshold has been identified by the Supreme Court in *In re A Ward of Court* in the requirements that there should be "clear and convincing proof having regard to the gravity of the decision" referred to earlier, and that "the court should not draw its conclusions lightly or without due regard to all the relevant circumstances including the consequences …" (*per* Denham J. at p. 155)."[396]

In the English case of *In re T (Adult: Refusal of Treatment)*[397], quoted with approval in *Fitzpatrick*, Lord Donaldson MR addressed the position in respect of clarity as follows:

> "It is well established that in the ultimate the right of the individual is paramount. But this merely shifts the problem where the conflict occurs and calls for a very careful examination of whether, and if so the way in which, the individual is exercising that right. In case of doubt, that doubt falls to be resolved in favour of

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[394] *G v An Bord Uchtala* [1980] IR 32 at 34.

[395] *In Re a Ward of Court*, supra note 14, at 127.

[396] *Fitzpatrick v FK*, *supra* note 4 at 38.

[397] *In re T, supra* note 149; quoted with approval by the Irish High Court in *Fitzpatrick v FK*, *supra* note 4 at 30.

> the preservation of life for if the individual is to override the public interest, he must do so in clear terms."[398]

While these judgments relate to the evidentiary standard of proof in such matters, it is a necessary correlation that the courts would also apply this standard to the lawfulness of an ACD. Therefore, the making of an ACD, should be carried out in line with this standard of clarity. The details of what will amount to sufficient clarity is a matter for the making of an ACD, but it is arguable that an ACD made in a manner that leaves the individual's wishes open to interpretation, particularly where the right to life is at stake, could be overturned by a court.

The UK cases of *W Healthcare NHS Trust v H* and *HE v A Hospital NHS Trust* provide examples of where a court overturned previously expressed healthcare wishes on the basis of lack of clarity.[399] The first case concerned an application to reinsert a PEG feeding tube into the patient, who was suffering from advanced multiple sclerosis and did not have the capacity, at the time of the application, to communicate her wishes. The Court heard evidence from the patient's family that she had previously expressed the wish that she "didn't want to be kept alive by machines" and that she did not want to be kept alive if the time came that she could not recognise her family.[400] In relation to previously expressed healthcare wishes in general, the Court stated:

> "If we say this clearly at a time when we are capable of expressing our wishes, then that clear declaration is binding on those who would have the responsibility for our care when we are no longer competent. But the declaration has to be clear and it has to be referable to the particular circumstances."[401]

In relation to the evidence of the orally expressed wishes of the patient, the Court found as follows:

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[398] *In re T, supra* note 149 at 112.

[399] *W Healthcare NHS Trust v H*, *supra* note 5.

[400] *Ibid* at 836-837; *HE v A Hospital NHS Trust*, *supra* note 371.

[401] *W Healthcare NHS Trust v H*, *supra* note X at 838. Also, in *In re T (Adult: Refusal of Treatment)* [1993] Fam 95 at 103, Lord Donaldson MR said: "an anticipatory choice … if clearly established and applicable in the circumstances-two major 'ifs'-[will] bind the practitioner."

> "The trouble about that approach, as a matter of law, is that she has not catered for every possible eventuality. Certainly she has catered, probably effectively, for situations where she would not wish artificial means of preventing her from submitting to an infection or what were formerly used as life support machines".[402]

Following on from this, the Court found that the patient previously expressed wishes were not "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."[403]

*HE v A Hospital NHS Trust* concerned a woman who had previously converted to the Jehovah's Witness faith and who subsequently required lifesaving medical treatment for congenital heart disease, including a blood transfusion. The patient had formally executed an ACD setting out her rejection of blood products based on religious beliefs. Her father argued that the ACD lacked validity as there had been a refutation by the patient of her faith prior to her hospitalisation, evidenced by her marriage to a Muslim man and her non-attendance any at Jehovah's Witness services. The Court found that the patient's behaviour had revoked the ACD, as it destroyed the fundamental assumption upon which it was based. In relation to the requirement of clarity of an ACD, Munby J stated:

> "Where life is at stake the evidence must be scrutinised with especial care. Clear and convincing proof is required. The continuing validity and applicability of the advance directive must be clearly established by convincing and inherently reliable evidence... If there is doubt that doubt falls to be resolved in favour of the preservation of life."[404]

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[402] *W Healthcare NHS Trust v H*, *supra* note 5 at 839.

[403] *Ibid* at 840. Having rejected the evidence of the previously expressed wishes, the Court decided the matter based on the "best interest" of the patient, being the reinsertion of the feeding tube.

[404] *HE v a Hospital NHS Trust*, *supra* note 371 at paragraph 46.

The Court in *HE v A Hospital NHS Trust* also found that ACD must be inherently revocable as an irrevocable ACD would be against public policy.[405]

It is likely that an Irish court would follow this approach in relation to clarity where the right to life is at stake. Further to this, even where the right to life is not at stake, a clear, unambiguously expressed ACD is more likely to meet the rest of the requirements covered in this Chapter.

## 5.5 Is Legislation Required for the Use of ACDs?

The Law Reform Commission of Ireland advises that the use of ACDs should be provided for by legislation. There is an argument that legislation would clarify the use of ACDs and allow people to avoid potentially sad and unpleasant litigation on issues that are raised in the application of an ACD. As noted by the English High Court judge in the case of *W Healthcare NHS Trust v H*: "To advocate for the speedy death of a very near and beloved relative is not a task one would wish upon one's worst enemy"[406]

Some jurisdictions have implemented the use of ACDs through legislation.[407] In the United Kingdom, the Mental Capacity Act 2005 provides for the making of an "advance decision" in relation to medical treatment. Under this legislation, an individual, if they have capacity, may make an advance decision specifying that treatment not be carried out or continued should that individual lack capacity at the time the treatment is proposed.[408]

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[405] Munby J stated: "An advance directive is inherently revocable. Any condition in an advance directive purporting to make it irrevocable, any even self-imposed fetter on a patient's ability to revoke an advance directive, and any provision in an advance directive purporting to impose formal or other conditions upon its revocation, is contrary to public policy and void. So, a stipulation in an advance directive, even if in writing, that it shall be binding unless and until revoked in writing is void as being contrary to public policy." See *HE v a Hospital NHS Trust*, *supra* note 371 at paragraph 46.

[406] *W Healthcare NHS Trust v H*, *supra* note 5 at 837.

[407] For example in Scotland, Section 275, Mental Health (Care and Treatment) (Scotland) Act 2003 provides for the making of an advance statement wherein a person can specify how they wish to be treated for mental disorder.

[408] Section 24, United Kingdom, Mental Capacity Act 2005 [Mental Capacity Act 2005] For the purposes of the act, "a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.", see Section 2, Mental Capacity Act 2005. Section 3, Mental Capacity Act 2005 clarifies that "a person is unable to make a decision for himself if he is unable—(a)to understand

The decision must be in writing and witnessed.[409] The United Kingdom legislation provides that a valid advance decision[410] has the effect of a contemporaneously made refusal of treatment and a physician will not incur liability for not carrying or continuing the specified treatment.[411] Interestingly, there is no requirement that the decision is informed and the validity of the advance decision is a matter of form and capacity.

The United Kingdom legislation clarifies that an ACD can be made and the form that the ACD should take, which is of assistance to individuals who are concerned about these issues. However, I believe that the United Kingdom's legislative provisions do no more than is already provided for by the common law on refusal of treatment. Indeed, in my opinion, the provisions of this legislation are narrower than the common law provisions as the legislation only covers refusal of treatment, and therefore does not provide for ACDs that consent to future care.[412]

Despite the clarity that legislation can generally introduce, I have particular concerns with any recommendation to legislate in relation to the use of ACDs. First, a mere recommendation to legislate does not resolve the issue of the use of ACDs by individuals who are currently seeking to formalise their health care wishes. This concern is self-explanatory and I have aimed to give some resolution to this issue by setting out the criteria of a lawful ACD. Second, legislation alone may not provide sufficient clarity for the execution of ACDs to prevent parties in particularly contentious situations from resorting to the courts for additional clarification.[413]

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the information relevant to the decision, (b)to retain that information,(c)to use or weigh that information as part of the process of making the decision, or(d)to communicate his decision (whether by talking, using sign language or any other means)." This reflects the test in *Re C*, *supra* note 160.

[409] Section 25(6), United Kingdom, Mental Capacity Act 2005.

[410] Section 25, Mental Capacity Act 2005.

[411] Section 26, Mental Capacity Act 2005.

[412] The Quebec Legislature is currently addressing the issue of ACDs in draft legislation, Bill 52, *An Act Respecting End of Life Care* 1st Sess, 40th Leg, Quebec, 2013 [Bill 52]. Bill 52, as currently drafted, provides that individuals may use ACDs to specify what care they do and do not consent to in the event of incapacity. See section 45, Bill 52.

[413] In relation to the medical treatment decision-making, this was seen in the case of *Rasouli*, *supra* note 349. I discuss this case above in section 5.3.2.

Most importantly, legislation may impinge on the exercise of the right to autonomy. To ensure that individuals can exercise their right to autonomy as freely as possible through the use of ACDs, it is important that legislation does not require a disproportionate amount of formality in the making of a valid ACD.[414] I would point to the Draft Mental Capacity (Advance Care Directive) Bill 2009, which is appended to the Law Reform Commission Recommendations on ACDs.[415] Section 3(b) of the draft Bill states "that an advance care directive should be made on the basis of informed decision-making."[416] As I have set out above, the issue of informed decision making is not clear in relation to the validity of ACDs. The requirement under Section 3(b) ignores the right to waive receiving information as a part of the right to autonomy.[417] The draft Bill does not define "informed decision-making" and therefore does not resolve this issue. It is clear that there is a common law principle that a competent person may refuse medical treatment for whatever reason.[418] Legislation should not be drafted in a manner that would encroach on this right.

Legislation should not constrict rights that are already protected under the common law. A pertinent example of legislation that narrows the common law position is found in section 53 and 54 of the Assisted Decision-Making Bill 2013.[419] As currently drafted, these sections appear to protect a physician from legal liability, including battery, if they treat a "relevant person"[420] without first obtaining their consent.[421] Section 54 provides

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[414] As currently drafted, Bill 52 requires a more formal version of an ACD than is set out in legislation from other jurisdictions. Bill 52 will require that ACD are notarised or witnessed in order to comply with the Bill's provisions. See Section 46, Bill 52.

[415] LRC, Advance Care Directives, *supra* note 12 at 112-124.

[416] LRC, Advance Care Directives, *supra* note 12 at 114

[417] See section 5.2.

[418] See *In Re a Ward of Court*, *supra* note 14 at 156; *Fitzpatrick v FK*, *supra* note 4 at 40-42.

[419] I discuss this Bill above in section 5.4.2.

[420] Section 2, Assisted Decision-Making Bill 2013, defines a "relevant person" as "a person whose capacity is being called into question or may shortly be called into question".

[421] Section 53 (2) Assisted Decision-Making Bill 2013 states "(2) An informal decision-maker who, in taking or authorising the taking of an action in respect of a relevant person, acts in compliance with the provisions of this Act shall not incur any legal liability which he or she would not have incurred if the relevant person—(a) had the capacity to consent in relation to the action, and

that a physician is not entitled to take any action where they have knowledge, or reasonably ought to have knowledge of a relevant decision made under the Assisted Decision-Making Bill 2013.[422] This does not allow for previously expressed wishes that do not come within the framework of the Bill. My interpretation of this provision is that it appears to allow for the lawful imposition of treatment on a person, who may not lack capacity, without their consent. The right to pursue a declaration of legal liability in such circumstances is an essential element of the exercise of the right to autonomy. In order for a right to be meaningful, there must be recourse to pursue a breach of that right. The Ontario court in *Malette v Shulman* stated:

> "The right of a person to control his or her own body is a concept that has long been recognized at common law. The tort of battery has traditionally protected the interest in bodily security from unwanted physical interference. Basically, any intentional nonconsensual touching which is harmful or offensive to a person's reasonable sense of dignity is actionable. . . . Thus, as a matter of common law, a medical intervention in which a doctor touches the body of a patient would constitute a battery if the patient did not consent to the intervention."[423]

As currently drafted Sections 53 and 54 seriously limit this right to autonomy and make for bad legislation.

Once enacted, legislation has the presumption of constitutionality, making it harder to challenge. This is a well-known principle of Irish constitutional law.[424] In the decision of the Irish Supreme Court in *Pigs Marketing Board v Donnelly (Dublin) Ltd,* Hanna J stated:

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(b) had given consent to the informal decision-maker to take or authorise the taking of the action." This section does not extend to non-therapeutic sterilisation, the withdrawal of artificial life-sustaining treatment, or the donation of an organ.

[422] As discussed in section 5.4.2

[423] *Malette v Shulman*, *supra* note 104 at 423.

[424] In *Buckley and others (Sinn Féin) v Attorney General and Another* [1950] IR 67 at 80, the Irish Supreme Court explained that "Such a principle, in our opinion, springs from, and is necessitated by, that respect which one great organ of the State owes to another."

> "When the Court has to consider the constitutionality of a law it must, in the first place, be accepted as an axiom that a law passed by the Oireachtas, the elected representatives of the people, is presumed to be constitutional unless and until the contrary is clearly established."[425]

Therefore any legislation placing limits on the use of ACDs may very well go over and above what is currently allowed under common law and yet, if enacted, would be prove very difficult to challenge.

The use of ACDs is better dealt with under the practice guideline for medical practitioners.[426] As noted at the beginning of this chapter, these guidelines already state that an advance decision has the same "ethical" effect as a contemporaneously made decision.[427] I suggest that this provision is strengthened in favour of the right to autonomy by providing that an advance decision has the same "legal" effect as a contemporaneously made decision.

I would suggest that clarity in relation to the form of an ACD could be appropriately achieved by simple amendment to the Irish legislation already in place in relation to the use of enduring powers of attorney. I recommend that powers of attorney could be used as a form of ACD by extending the definition of "personal care" under the relevant legislation to include health care.[428] Although, I maintain that the form of ACD should be left as informal as possible, and the use of enduring power of attorney would remain a recommendation to form rather than a requirement.

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[425] *Pigs' Marketing Board v Donnelly* (Dublin) Ltd [1939] IR 413,417, approved in *Curtin v Dáil Éireann* [2006] 2 IR 556 at 620.

[426] As recommended by the Court in *Fitzpatrick v FK*, *supra* note 4at 103.

[427] Ireland, Irish Medical Council, Guide to Professional Conduct and Ethics for Registered Medical Practitioners, 7th edition (Irish Medical Council, 2009) at paragraph 41.2.

[428] As discussed above in section 5.4.2. Section 40(2), Assisted Decision-Making Bill, as currently drafted will extend the definition of "personal care" to include medical treatment.

## 5.6 Conclusions

The absence of formal requirements for drafting an ACD is unhelpful to those seeking to formalise their healthcare wishes, particularly in cases where there is a deeply held motivation to ensure that such wishes are followed. Nonetheless it is my opinion that that legislation is not required for the use of ACDs under Irish law and that any ACD meeting the criteria set out in this chapter would be lawful in Irish legal jurisdiction.

I recommend that if legislation is enacted to provide for the use of ACDs, any such legislation ought to be drafted in a manner that appropriately respects the right to autonomy. I have set out above some recommendations on how clarity could be achieved in the Irish law on ACDs in a manner which upholds the right to autonomy.

## Chapter 6: Conclusion

Thinking ahead in relation to medical treatment decision-making is not easy, especially for the young and the healthy. In the High Court decision in *In Re a Ward of Court* Lynch J said:

> "Moreover, it must be difficult for a young person in perfect health to give a rational direction as to the prolongation or otherwise of his health if he should have the misfortune to become drastically disabled so as to require some artificial life support."[429]

Still, as I have set out in this thesis, it cannot be assumed that an individual's medical treatment wishes will be followed if there are concerns as to the capacity of the individual to make such decisions. The exercise of the right to autonomy may be affected in such a situation. In this thesis, I propose that formalised treatment wishes in an ACD may assist in preserving an individual's autonomy in relation to medical treatment in anticipation of any incapacity. I looked at cases where an individual's health care wishes were not followed and suggested that these cases may have had a different outcome for patient autonomy if the individual concerned had made an ACD.

It is clear that there are no legislative provisions on the use of ACDs under Irish law. Despite this, I believe that the use of ACDs is *prima facie* lawful once certain criteria are met. In particular, the right to autonomy under Irish constitutional law allows for the use of ACDs. I propose that, under current Irish law, ACDs have the same legal and ethical effect of a contemporaneously made refusal of treatment.

I propose that a lawful ACD under Irish law depends on capacity, voluntariness and clarity. In addition, the ACD should not request measures that would be unlawful, such as euthanasia. Once these criteria are present, the right to autonomy, as interpreted by the Irish courts, allows the making and application of an individual's formalised advance wishes in relation to medical treatment.

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[429] In *Re a Ward of Court*, *supra* note 14 at 8.

Other jurisdictions have dealt with the use of ACDs through the implementation of legislation. I agree that there could be some benefit to the drafting of Irish legislative provisions in relation to ACDs. For example, legislation could give clarity as to the form of an ACD. However, I propose that legislation is not required for the use of ACDs and may, depending on the legislative provisions, encroach on the exercise of autonomy in relation to the use of ACDs.

Instead of legislation, I suggest that the use of ACDs is provided for under the Irish guidelines for medical practitioners. I also suggest that the form of ACDs can be appropriately covered by amendment to the extant legislative provisions in relation to enduring powers of attorney; however I recommend that, in accordance with the exercise of the right to autonomy, there should be no mandatory requirement as to form of ACDs.

An issue that I have not been able to fully address in this thesis is the criticism that ACDs may not adequately protect the exercise of autonomy unless they are made in an informed manner. As I set out in Chapter Five, the requirement of informed choice in relation to the use of ACDs is a grey area. It appears that the application of the principle of autonomy precludes making informed consent a formal requirement to a valid advance healthcare directive; however, not all ACD are created equal and the courts in some common law jurisdictions (including the United Kingdom and Canada) have refused to uphold ACDs where there is a lack of clarity in the provisions.[430] Obtaining professional advice and counselling before drafting an ACD could assist in the clear, understandable and accurate recording of an individual's treatment wishes in the directive. In order to protect the value of autonomy and not to limit its exercise as a right, I thus recommend a multi-disciplinary approach to the making of an ACD. This approach would include referral to counselling and consultation with medical professionals in relation to treatment options and clarity of terminology.

In this respect, I suggest that further research be carried out into the approach to the making of an ACD which best ensures the autonomy of the individual concerned.

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[430] See section 5.4.4.

Furthermore, individuals should be made aware of their rights in relation to medical treatment decision-making before a crisis occurs. Decision-making in relation to medical treatment should not be a moveable feast dependant on the vagaries of litigation. There should be certainty that an individual will not be treated medically in a manner that goes against their wishes, where those wishes are known.

A final issue which requires more resolution is that of the interaction between advance medical treatment planning and mental health. Few jurisdictions appear to be willing to address this issue on this basis that many mental health issues result in fluctuating capacity.[431] However, following my research into this area for this thesis, I believe that the continued carrying out of treatment without due regard for the rights of mental health sufferers to make their own health care decisions is unconscionable. Of course, there are often genuine concerns about the functioning of autonomy when there is a mental health disorder manifest. Nevertheless, there appears to be a lack of rigour to the approach taken by the courts generally with respect to mental health; an approach often without due regard to the potentially devastating implications of a finding of incapacity. Medically, we still do not know where the line is drawn between the mental and the physical, and the law on this issue in particular lags far behind the medical position, notwithstanding concerns about the over-medicalisation of society.[432]

This is not an issue that has an obvious solution. However, it appears that public opinion leans towards closer scrutiny of the fettering of the exercise of the right to autonomy. As I conclude this thesis, an international uproar has arisen in relation to a court order made by an English district court allowing the carrying out of a Caesarean section, without consent, on a pregnant woman on the grounds that she suffers from bipolar disorder.[433] While the order raises serious concerns, the critical response of the English parliament

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[431] See, for example, section 275, Scotland Mental Health (Care and Treatment) Act 2003.

[432] There is potential for error, borne out of societal conditions, in psychiatric diagnosis. Historically, there has been a tendency to medicalise “deviant” behaviour, for example the running away of slaves was medicalised as the condition of "Drapetomania" See Norman Daniels, “Health Care and Distributive Justice”, (1981) 10, *Philosophy and Public Affairs*, 146 , at 156.

[433] Lisa Hallgarten, “A caesarean must be a choice – whatever the circumstances” The Guardian, see online <www.theguardian.com/commentisfree/2013/dec/02/caesarian-choice-allegations-forced-intervention-pregnancy-childbirth>; See the judgment in *In Re P (A Child*) [2013] EW Misc 20 (CC).

and mental health charities to the making of the order is somewhat reassuring in relation to the preservation of the right to autonomy.[434] Lawyers cannot rest easy on the basis of prior jurisprudence; protection of the exercise of the right to autonomy requires constant vigilance and scrutiny.

[434] Matthew Taylor, “”MP queries forced Caesarean Section”, The Guardian, see online <www.theguardian.com/society/2013/dec/01/mp-queries-forced-caesarean-section>

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