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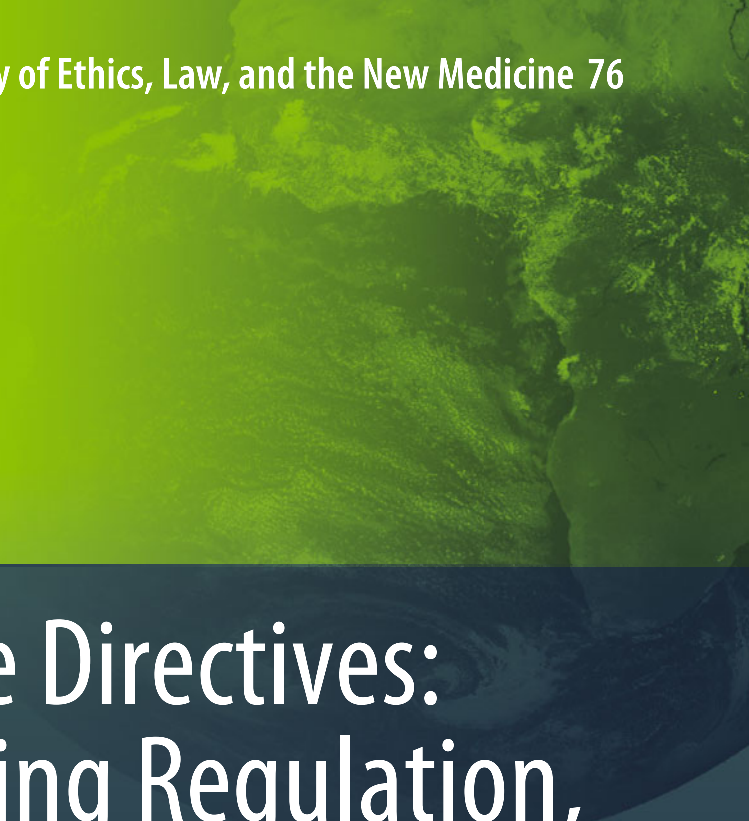

Hui Yun Chan

Advance Directives: Rethinking Regulation, Autonomy & Healthcare Decision-Making

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To my parents, with love

Foreword

Supported decision-making and healthcare partnerships. In the complex world of modern health care, there are many options for dealing almost every health challenge and we are emerging from two paradigms in health care which have distorted the landscape of ideal therapeutic relationships. The first paradigm was paternalistic —the idea that doctors and other health professionals know best and that patients should act very much in the suffering recipient role, following professional advice and accepting the outcome. That phase passed with the rile of contemporary bioethics and the model was supplanted in favour of a quasi-legal contact where the professional had the edge in terms of knowledge and power and the patient made the best deal they could with their own limited resources of knowledge and choice of movement. This approximated a contract in some settings but in others, a highly unequal agreement where one party had disempowered role and the other was on 'home turf'—territory they knew well. The essence of the relationship could be a mutually satisfactory arrangement or a cause for later dispute. I either event the role of education and empowering the patient was limited and not a pre-eminent part of the professional's duty.

Both have now lost ground and ethico-legal acceptance in the loci of medical care where ethics and law are most developed. In toe settings a model has begun to be developed where both doctor ande patient form an alliance in obtaining the therapeutic alliance that both partners feel is best given the challenge they are jointly facing. The challenge cannot be sequestered from the lived life of both and the outcome most to be desired is that which both contribute to making their therapeutic sim. Of course, in any straightforward of even moderately complex case the best outcome is one that would leave each as intact and restored to a sustainable ongoing life as possible.

That outcome allows the healthcare professional to exercise the skills that, in their professional judgment, they consider most applicable to the patient's need. That judgment must be made in the uncertain world of health futures and will reflect the experience and expertise of the professional and the actual health challenge presented by the patient's suffering. There is a great deal of judgment involved and the professional must do that cognitive work with humility, realism and diligence.

In that condition, the choices outlined to the patient will be well-informed by evidence, holistic in terms of the idiosyncratic factors that make each patient unique. Legal risks and potential liabilities form a part of an adequate profile on the entire situation but an open sharing of information and decision-making power is the most defensible and sound approach to the therapeutic dilemma and they jointly aim to negotiate perilously. If they can strike a golden mean in information and power-sharing between them, there will be a genuine joint ownership of what is happening that potentiates the best possible approach to therapy, when skillfully conducted and openly entered into.

That puts them, working as a team, in the very best position to confront unexpected (and even unwelcome) contingencies. That joint empowerment and synchrony of knowledge and intentions that are inherent in a supported decision-making model of health care is then the strongest basis of therapy going forward, most likely to produce the most acceptable (and able to be accommodated outcome for all. Being open with patients, constructing good and well-informed partnerships in health care and developing a shared fortitude in the face of adversity are the ideals on which our current evolution of health law and ethics should be based. The framework is both aspirational but also realistic and this work is a step in the direction of setting that out fully and accessibly to a wide audience who are then empowered to be as the leading edge of thinking in medical ethics and law rather than labouring with tools, techniques and attitudes that have been proved unfit for the purpose.

Otago, New Zealand Grant Gillett

Contents

Chapter 1
Introduction

In 1967, Robert Waskin shot his cancer stricken mother to death.[1] The jury returned a verdict of not guilty on the ground that the prosecution had "failed to show that he was of sound mind when he did it",[2] thereby excusing him of the indictment of murder in the first degree. His act in shooting his mother was motivated by compassion, watching the mother suffering from the unbearable effects of cancer.

Margaret Page[3] had sought to exercise her autonomy in refusing treatment in anticipation of debilitating conditions. She had, in 2010, refused to eat and starved herself to death following deterioration as a result of suffering from brain haemorrhage. Doctors who cared for her respected her refusal and she died 16 days later. While Margaret Page had her refusal respected, Lecretia Seales'[4] case had generated renewed interests in euthanasia and advance directives in New Zealand.[5] Seales suffered from brain cancer and had requested for assisted dying without criminal liabilities to the doctors and family members who helped her. Her request was refused.

In the UK, M, a minimally conscious patient was kept on artificial nutrition and hydration despite the family's appeal to withdraw treatment.[6] The family revealed that M had previously informed them that she would not want to be kept alive in such a condition. However, the court did not accept M's oral advance directive as binding. If M had formalised her wishes in an advance decision according to the law, it would have been binding on the healthcare professionals.

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[1] Luis Kutner "Due Process of Euthanasia: The Living Will: A Proposal" (1968–1969) 44 Ind L J 539.

[2] Ibid.

[3] Kiran Chug, Stacey Wood and Tim Donoghue "Margaret Page dies in rest home after 16 days" (2014) The Press Stuff.co.nz. http://www.stuff.co.nz/the-press/news/3532462/Margaret-Page-dies-in-rest-home-after-16-days. Accessed 20 October 2017.

[4] Rebecca Macfie "Dying wishes" (8 January 2015). http://www.listener.co.nz/current-affairs/health-current-affairs/dying-wishes/. Accessed 20 October 2017.

[5] Ibid.

[6] *W v M and others* [2011] EWHC 2443 (Fam).

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Margaret Page, Lecretia Seales and M demonstrated the challenges with having treatment refusal accepted as binding when it comes to life prolonging or life sustaining treatments. Robert Waskin illustrated the difficulties of the law in grappling with the person's inability to end the pain and suffering of a life from terminal illness. The inadequacy of the criminal law in recognising motive as an element of homicide had prompted Luis Kutner, an advocate for advance directives, to propose the concept of "living will".[7]

This book sheds light on the challenges and potentials of making healthcare decisions at the end-of-life using advance directives. It shows why some advance directives often end up being ineffective and explores strategies for improving their effectiveness. An advance directive will often not come to the attention of medical professionals—far less the courts—until the patient has lost capacity. Advance directives exemplify the kind of concern where practical questions of clinical treatment meet long standing conflicts of philosophical principles. The significance of advance directives within the broader context of consent in medical law is that in the absence of consent or prior expressed wishes, the default position is to treat people in their best interests, even if they would have refused such treatment had they been able to refuse consent. Thus, advance directives provide the opportunity for people to express their refusal to consent in the future when they become unable to do so, either in anticipation of debilitating conditions, or progressive illnesses such as Alzheimer's or Parkinson's. It offers the best evidence of what people would have wanted or refused before they lose the capacity to express such wishes. Such expressions provide an insight into the person's values, beliefs and preferences for medical treatment or hospital admissions, and help towards informing healthcare professionals about preferences for withdrawing or withholding treatments. It is often an important feature in healthcare decision-making which is brought to the fore when doctors and patients do not agree with the decision made, or where families differ in terms of continuity of treatment as illustrated by M above.

When one contemplates about future incapacity involving life and death situation, it reflects a sense of exercising the person's autonomy through expression of wishes. The gravity of the decisions, in turn, prompted these questions: What is the best way to ensure that the expression is valid and will be acted upon? How can we expect others to implement our wishes with their help? What steps have we taken to empower ourselves and be informed of the decision we are making? How have we maximised the person's participation in the decision? How have we assisted the person to form and express the person's preferences? These questions are considered appropriately throughout the book. It provides a new decision-making framework aimed at making advance directives legally effective, outlining the golden rules in the process of creating advance directives. This, in turn, is aided by a proposal to establish a system for the creation of a nation-wide approved document for advance directives. The system provides an option for people wishing to make advance directives that are more likely to be accepted as legally binding, while retaining the flexibility of making advance directives under the common law.

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[7] The concept and history of "living will", the origins for ADs will be explored in Chap. 2.

Advance directives have progressed over the decades since their beginnings as "living wills". They have taken a variety of forms and names, including a combination of power or attorneys and statement of preferences. Advance directives can be made orally or in writing and have been used as a general term referring to instructions regarding medical treatment, usually refusals, that are intended to be binding. This term however, does not carry a universal meaning. Countries utilise the term advance directives with different legal meanings, as such, they may or may not be binding on the healthcare professionals. For example, the English Mental Capacity Act 2005 uses the expression "advance decision to refuse treatment",[8] which has the same meaning as an advance directive, but does not employ the term "directive." Other commonly occurring terms used to refer to advance directives encompass terms such as "living will",[9] "health direction"[10] or "instructional directive".[11] In particular, the term "living wills" is often used interchangeably with advance directives. Indeed, the historical development suggests that "living will" is the more popular term used for instructions about treatment and known as the first generation type of advance directives. None of these terms, however, fully expresses both the advance and binding nature of advance directives that are the subject of this book.

The term adopted in this book is advance directives (ADs), which refers to instructions made by a competent person about the withdrawal and withholding of end-of-life treatment when that person becomes incompetent and that are intended to be binding on those involved in the person's end-of-life care. The term "directive" is used to indicate that it is intended to be legally binding on healthcare providers. The term "advance" is used to indicate that it is made before the person becomes incompetent and is intended to apply only after the person has lost competence, whether permanently or temporarily. Thus, an advance directive anticipates the kind of treatment that the patient envisages might be provided in the future, when the person becomes incompetent.

The only treatment decisions that will be considered here are those that a person could make contemporaneously. An advance directive is often made as part of a wider plan for future end of life treatment and care, commonly known as an Advance Care Plan (ACP). An ACP is the process of discussing and documenting, but is not limited to future health choices. This may include processes for recording patients' wishes for care in a living will or advance directive and for appointing a surrogate decision maker in a document such as an enduring power of attorney.[12] Matters that are included in an ACP may range from lifestyle choices, funeral plans, values history

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[8] A term used in England and Wales when referring to advance directives that are legally binding.

[9] The term was first coined by Luis Kutner who proposed a device that enables competent people to refuse treatment when they become incompetent.

[10] This term is used in the Australian Capital Territory.

[11] This term is used in Canada generally to refer to an advance directive that expresses wishes for health or personal care. It can also be broad enough to include the appointment of substitute decision-makers.

[12] Ian Kerridge, Michael Lowe and Cameron Stewart (eds) *Ethics and Law for the Health Professions* (4th ed, The Federation Press, NSW, 2013) at 377.

or retirement home plans. An ACP serves as a foundation for a more formalised form in the later stages of the discussion.

Various jurisdictions have put in place measures to regulate the use of ADs, ranging from prescriptive rules and requiring compliance with formal requirements, to a broadly permissive approach, where the use of ADs is permitted only in specified circumstances. Although the right to choose and the right to refuse treatment are now widely accepted in the common law world, the extents to which ADs are binding are however, controversial. The contexts in which the countries approaches differ contribute to the diversity of approaches, in terms of scope and forms.

The cases, on the other hand provided some insights into how ADs are dealt with. They revealed interesting judicial approaches towards treatment refusals. The cases showed that, despite the presumption of capacity, courts would often require proof of capacity that people knew what they were refusing at the time the ADs were made. In the small number of cases where ADs were upheld, it was because either the doctors or the courts had the opportunity to verify these expressions of autonomy by communicating with the patients before capacity was lost. Additionally, the courts' approach towards ADs suggested that they readily erred towards the presumption of saving life when doubts arose about their validity.

These developments demonstrate some resistance to binding ADs, which reflect a reality that the uncertainties with implementing ADs can be principally attributed to the lack of clarity in the decision-making process. In a contemporaneous refusal, the refusal can be confirmed, with the opportunity to clarify the wishes of the person or any other aspects of the decision that raises doubts. Unlike a contemporaneous refusal, then, an AD typically does not reveal the circumstances under which it was made. Judgments about the capacity, voluntariness and knowledge of the person who wrote it will typically have to be made retrospectively. Likewise, it will be difficult, if not impossible, to verify that the AD—which may have been written some time before their loss of competence—continued to represent their views, especially in view of changing prognoses and medical advances.

The careful scrutiny of ADs underpins various reasons for accepting or rejecting ADs. Supporters of ADs proposed that people should have the right to determine how they die. The conscious decision to make an AD gives it the right to be respected, as an expression of patient autonomy. The opponents meanwhile argued that the concept of AD is fundamentally wrong and that they are impractical to implement. We can see that while ADs developed in an environment that challenged paternalism, they are accepted as part of medical decision-making on the basis of exercising individual autonomy. Although autonomy is more commonly understood as non-interference, this interpretation of autonomy is inadequate for ADs. An empowering and supportive approach is needed to help people create ADs that are more likely to be accepted as binding. This approach is known as supported decision-making.

I emphasise the importance of engaging in supported decision-making in the process of creating ADs, as an essential feature in ensuring that the person who makes the AD is appropriately supported to arrive at a decision. A supported decision-making approach pre-empts challenges to the validity of an AD in respect of the person's capacity, voluntariness and understanding of the nature and consequences of refusing treatment at the time the AD is made. This approach encourages support to either build the person's capacity in anticipation of, or during the process of making the ADs. Questions about whether the process should be formalised or not will also be considered, taking into account the examples from countries that adopted formal requirements for making ADs. Some recommendations in the form of golden rules for making ADs are included in the book, which embraces supported decision-making. These steps, if carried out adequately will persuade courts that ADs can be an effective vehicle for the exercise of autonomy.

Chapter 2
The Making of Advance Directives

2.1 Advance Directives in Medical Treatment

2.1.1 Beneficence and the Rise of Patient Autonomy in Doctor-Patient Relationship

Medical practices have evolved since the Hippocratic traditions.[1] Under the Hippocratic tradition, doctors were responsible for the wellbeing of the patient, and for keeping them from harm, which gave rise to the practice of benevolent deception. This may be seen as medical paternalism today. Pursuant to this practice, doctors, having the authority to diagnose, treat and dispense medicine, were encouraged to withhold any information that was deemed to harm the patient's prognosis.[2] They are required to refrain from inflicting harm to the patient (non-maleficence)[3] and act positively towards promoting good or removing harm (beneficence).[4] A doctor's etiquette was viewed as essential in gaining patients' trust, a feature that distinguished doctors socially from the ordinary people.[5] This naturally led to no role for patient participation in treatment, implying a superior authority and knowledge over the laymen. Perhaps, it was this "superiority" that led to the mistaken assumption that doctors were best positioned to decide what was best for the patient. As we will see, advance directives (ADs) developed in response to practices that are perceived as paternalistic in a clinical setting.

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[1] Jonathan F Will "A Brief Historical and Theoretical Perspective on Patient Autonomy and Medical Decision Making" (March 2011) 139(3) Chest 669.

[2] Ibid.

[3] Tom L Beauchamp and James F Childress *Principles of Biomedical Ethics* (5th ed, Oxford University Press, USA, 2001) at 115.

[4] Ibid.

[5] Ruth R Faden and Tom L Beauchamp *A History and Theory of Informed Consent* (Oxford University Press, New York, Oxford, 1986) at 62.

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A doctor's authority however does not go unchallenged. Historical events have contributed to the increasing awareness of autonomy; such as the discovery that doctors in the Nazi regime had been conducting harmful medical experiments on prisoners without their consent. The Nuremberg Code was a significant product of the Nuremberg Trials which exposed the flagrant breaches on research experimentation involving human subjects and cemented the right of all medical research participants to consent.[6] The Declaration of Helsinki was approved by the World Medical Association in 1964 primarily in response to the Nazi atrocities.[7] Other events involving human experimentation that came to light after the publication of these international instruments include the United States Public Service Study of Syphilis in the Untreated Negro Male scandal where 600 black men with syphilis were not treated, with devastating health consequences where women and children were harmed when the disease was passed to them.[8] Although it was not discovered until some 40 years later, the importance of obtaining consent from human subjects in medical research was further emphasised.[9] The scandal caused uproar after it became public which then led to a public enquiry, and subsequently, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research was established under the National Research Act 1974 to ensure that the rights of research study participants were protected.[10]

Notions of human rights within the health context increasingly came under the spotlight internationally. The Universal Declaration of Human Rights ("UDHR"), adopted by the United Nations General Assembly in 1948, sought to affirm the protection of human rights.[11] This affirmation is based on acknowledging the "inherent dignity and of the equal and inalienable rights of all members of the human family as the foundation of freedom, justice and peace in the world."[12] Besides the 1948 UDHR, the Council of Europe adopted the European Convention on Human Rights in 1950, also in response to the atrocities of the Nuremberg Trial. A subsequent European Convention on Human Rights and Biomedicine was adopted in 1997 setting out the rights and obligations of patients and doctors. The basis for which the rights of human being must be respected was premised on protecting the dignity and

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[6] Nan D Hunter "Rights Talk and Patient Subjectivity: The Role of Autonomy, Equality, and Participation Norms" (2010) 45 Wake Forest L Rev 1525 at 1530.

[7] John M Last (ed) *A Dictionary of Public Health* (Oxford University Press, Oxford, 2007).

[8] "The Tuskegee Timeline" (2013) Centers for Disease Control and Prevention. www.cdc.gov/tuskegee/timeline.htm. Accessed 18 November 2017; "Presidential Mandate" Tuskegee University National Center for Bioethics in Research and Health Care. http://tuskegeebioethics.org/presidential-mandate/. Accessed 5 July 2018.

[9] Nan D Hunter "Rights Talk and Patient Subjectivity: The Role of Autonomy, Equality, and Participation Norms" (2010) 45 Wake Forest L Rev 1525 at 1533.

[10] Eleanor Singer and Felice J Levine "Protection of Human Subjects of Research: Recent Developments and Future Prospects for the Social Sciences" (Spring, 2003) 67(1) The Public Opinion Quarterly 148.

[11] Johannes Morsink *The Universal Declaration of Human Rights: Origins, Drafting and Intent* (University of Pennsylvania Press, Philadelphia, USA, 1999) at 36.

[12] Ibid., at 313.

identity of humans and recognising the primacy of humans, in which their interests and welfare prevailed over societal and scientific interests.[13] These events illuminated an unchecked doctor's authority on patients at that time. The aftermath of the events cemented a patient's right to be consulted and a doctor's and medical researchers' obligation towards respecting the right to be left alone unless consent has been obtained. The World Medical Association recently reflected the increasing importance of respecting patient autonomy in the current version of the physician's pledge patients.[14]

The burgeoning medical discoveries in the 20th century saw the invention of cardiopulmonary resuscitation, chemotherapy, the heart-lung machine, the pacemaker and defibrillator, new drugs, organ transplantations as well as CT scans.[15] These rapid medical advances have transformed medical practice in terms of creating new treatment methods and opening avenues for new medical research[16] which seemingly translate hopes into needs with the endless technological possibilities.[17] These medical and technological advancements however, gave rise to ethical concerns. For example, advances in medicine that enabled lives to be prolonged, the uncertainties of when death actually occurs, ethical issues on abortion and organ transplants challenged the "old medical ethics."[18] The various patients' rights declarations and continuous medical advancements provided the foundation for bioethics to emerge—a discipline that applied ethical theories to the problems that arise from political, scientific and cultural changes.[19]

The cumulative effect of the recognition of patient rights arising from the events above, gained the attention of intellectuals and scholars, notably with the establishment of the Hastings Center and the Kennedy Institute. These academic institutions questioned the human values in the light of the medical progress, such as issues on prolonging life and death and end-of-life concerns.[20] Faced with growing concerns on these pressing issues of the time, the Presidential Commission on Ethical

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[13] Arts 1, 2 Universal Declarations of Human Rights.

[14] World Medical Association *Declaration of Geneva* 2017.

[15] "Medical Changes from 1945" (2014) Historylearningsite.co.uk. http://www.historylearningsite.co.uk/medical_changes_from_1945.htm. Accessed 6 November 2017.

[16] "The 1960s: Medicine and Health: Overview" (2001) Encyclopedia.com. http://www.encyclopedia.com/doc/1G2-3468302401.html. Accessed 5 November 2017.

[17] Mark J Hanson "The Idea of Progress and the Goals of Medicine" in Mark J Hanson and Daniel Callahan (eds) *The Goals of Medicine: The Forgotten Issue in Health Care Reform* (Georgetown University Press, Washington DC, 1999) at 144.

[18] Daniel Callahan "Bioethics and Policy—A History" in Mary Crowley (ed) *From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns* (The Hastings Center, Garrison, NY, 2008) ix–x.

[19] Daniel Callahan "Bioethics and Policy—A History" in Mary Crowley (ed) *From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns* (The Hastings Center, Garrison, NY, 2008) ix–x. See also John-Stewart Gordon, "Bioethics" Internet Encyclopedia of Philosophy. http://www.iep.utm.edu/bioethic/. Accessed 15 November 2017.

[20] Alfred I Tauber "Historical and Philosophical Reflections on Patient Autonomy" (2001) 9 Health Care Analysis 299 at 303.

Concerns in Biomedicine was established to provide ethical oversight for federal sponsored research.[21] The growth of patient rights formalised patient autonomy in the form of legal rights, which led to less hesitation on the part of patients in bringing negligent suits against doctors.

In tandem with these movements, the medical profession in the US responded with the publication of the Patient Bill of Rights in 1973, which became the charter for most American Hospital Association (AHA) member hospitals across the US.[22] It has since been revised in 1992 and replaced with the Patient Care Partnership in 2001.[23] The right to make ADs was included in the Bill. In the realm of medical treatment, where patient autonomy slowly gained acceptance, the right to give informed consent also extended to the right to refuse treatment, even when it resulted in the death of the person. The idea of ADs is thus embedded in respecting the autonomous choice of the person.[24] The duties of doctors and rights of patients are also recognised internationally, for example, the World Medical Association which published its Declaration of Lisbon on the Rights of the Patient in 1981.

A significant development that burgeoned along with the technological progress (particularly life sustaining treatment) and growth in bioethics is the question of euthanasia. ADs have their roots in the right-to-die movement and the euthanasia debate. This perhaps makes it easier to identify why misunderstanding exists when people equate ADs with euthanasia. The AD connection to euthanasia and right-to-die is echoed by the World Federation of Right to Die Societies which, in its 1976 Tokyo Declaration, called for legalisation of living wills as an expression of human rights, and respecting a person's wish to die with dignity.[25] Euthanasia advocates viewed the acceptance of living wills as a stepping stone towards the ultimate goal of accepting suicide and assisted suicide legally and socially.[26]

The living will concept was suggested in the Euthanasia Society of America circles as early as 1949, but only became popular after Luis Kutner, an instrumental figure in the history of ADs, re-introduced the idea in the late 1960s.[27] Kutner's living will idea was further advanced soon after the publication of another article in

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[21] Ibid., at 302.

[22] "Changes in Hospital Care: The Patient's Bill of Rights" (2014) Virginia Health Information. http://www.vhi.org/hguide_patientbill.asp. Accessed 23 October 2017.

[23] Ibid.

[24] Jonathan F Will "A Brief Historical and Theoretical Perspective on Patient Autonomy and Medical Decision Making Part II: The Autonomy Model" (June 2011) 139(6) Chest 1491 at 1496.

[25] "History of the World Federation of the Right to Die Societies" The World Federation of Right to Die Societies. http://www.worldrtd.net/history-world-federation-right-die-societies; "Tokyo Declaration of August, 1976" The World Federation of Right to Die Society. http://www.worldrtd.net/it/news/tokyo-declaration-august-1976. Accessed 5 June 2017.

[26] Ian Dowbiggin *A Concise History of Euthanasia: Life, Death, God and Medicine* (Rowman & Littlefield Publishers, Inc., USA, 2005) at 125.

[27] Ian Dowbiggin *A Merciful End: The Euthanasia Movement in Modern America* (Oxford University Press, New York, 2003) at 121.

1987.[28] His passion in libertarian rights-based work and advocacy had contributed to the foundation for the living will concept, as a mechanism for promoting autonomy in the event of future mental incapacity. The increasing importance of the right to privacy in the US between the 1960s and 1970s fuelled huge demands for living wills.[29] Kutner's efforts in promoting living wills soared with 5000 copies of living wills distributed in 1969,[30] while media promotion resulted in about three million living wills being distributed by 1978.[31] California became the first state to legislate for living wills in 1976.[32]

The concepts of rights and liberty that gained ground throughout the decades, and became particularly prominent in the 1960s social transformation, influenced the individual's private life. Living wills prospered under these circumstances. These influences came to light with greater challenges to the doctor-patient relationship, particularly the clinical authority that was previously characterised as belonging to the doctor's domain. This landscape however went through some changes, primarily with the right to informed consent which emerged in the US courts, signifying the recognition of an individual's right in medical treatment. *Schloendorff v Society of New York Hospital*, a decision of the New York Court of Appeal in 1914 established the principle of informed consent in the North American jurisprudence,[33] which has since been endorsed in the Commonwealth jurisdictions, as an affirmation of the right to bodily integrity and self determination. In the well-known words of Cardozo J[34]:

> Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages. This is true except in cases of emergency where the patient is unconscious and where it is necessary to operate before consent can be obtained.

In addition to *Schloendorff*, other judicial decisions emphasising the patient's right to give informed consent, and have their refusal of consent accepted, began to emerge, curtailing a doctor's authority to treat, and demonstrating a shift towards a patient-focused approach.[35] Cases emerging elsewhere represented a trend where a doctor's authority to treat no longer goes unchallenged, mostly dealing with a

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[28] Luis Kutner "The Living Will: The Epitome of Human Dignity in Coping with the Historical Event of Death" (1987) 64 U Det L Rev 661.

[29] Ian Dowbiggin *A Merciful End: The Euthanasia Movement in Modern America* (Oxford University Press, New York, 2003) at 121.

[30] Ian Dowbiggin *A Concise History of Euthanasia: Life, Death, God and Medicine* (Rowman & Littlefield Publishers, Inc., USA, 2005) at 124.

[31] Ian Dowbiggin *A Merciful End: The Euthanasia Movement in Modern America* (Oxford University Press, New York, 2003) at 121.

[32] Ian Dowbiggin *A Concise History of Euthanasia: Life, Death, God and Medicine* (Rowman & Littlefield Publishers, Inc., USA, 2005) at 124.

[33] *Schloendorff v Society of New York Hospital* 105 NE 92 (NY 1914).

[34] Ibid.

[35] *Salgo v Leland Stanford Jr Univ Bd of Tr* 317 P2d 170 (Cal Ct App 1957); also reaffirmed in *Canterbury v Spence* 464 F2d 772–790 (DC Cir 1972). The range of patient-centred approaches

doctor's duty to inform the patient to enable the patient to make a decision.[36] The recognition for the right to informed consent developed where gradually the right to refuse treatment was upheld.[37] However, this development was slow because courts were reluctant to make any sweeping reforms that dramatically altered the therapeutic relationship.[38] Although the cases that developed demonstrated an increasing recognition of patient rights, patient autonomy was not considered a predominant feature in a doctor-patient relationship yet, and the medical profession was somewhat protected from the growing recognition of patient autonomy.[39]

The concept of living wills gained more prominence in the months following the *Quinlan* trial in the late 1970s.[40] Although *Quinlan* did not deal directly with living wills, its much publicised litigation about whether Karen Quinlan had, as was alleged, expressed her wishes and whether these remarks could be relied upon had the effect of instilling a rush to assert control in the end-of-life in the event something happened. *Quinlan*[41] was the first case to deal with the tension between life prolonging technology and the right to refuse such treatment and that the common

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includes the necessity to inform the patient about the risks and complications in the case, even if it means that the patient will refuse to consent to treatment (*Salgo v Leland Stanford Jr Univ Bd of Tr* 317 P2d 170 (Cal Ct App 1957); the Court of Appeal held the doctor negligent in failing to disclose the risk of paralysis from the operation. (*Canterbury v Spence* 464 F2d 772–790 (DC Cir 1972); a patient's refusal to amputate gangrenous leg despite initial consent was respected (*Grace R Lane v Rosaria Candura* 376 N E 2d 1232 (Mass App Ct 1978); and the need for full disclosure of risks to radiation and offering alternative treatment options to the patient (*Irma Natanson, Appellant v John R Kline and St Francis Hospital and School of Nursing, Inc., Appellees* 354 P 2d 670 (Kan 1960).

[36] *Sidaway v Bethlem Royal Hospital Governors and others* [1985] 1 AC 871 concerning a doctor's duty to warn of treatment risks; *Rogers v Whitaker* [1992] 16 BLMR 148; *Hills v Potter and others* [1984] 1 WLR 130; *Reibl v Hughes* [1980] 2 SCR 880: Mr. Reibl was entitled to know the risk that as a result of the operation he could die or suffer a stroke of varying degrees of severity and the doctor failed to take sufficient care to communicate the purpose of the operation and to convey and assure that he understood the gravity, nature and extent of risks specifically attendant on the endarterectomy. In *Chester v Afshar* [2004] UKHL 41 the surgeon was held negligent even for failing to disclose an inherently small risk regardless of when the operation is carried out.

[37] *Cruzan v Harmon* 760 SW 2d 408 (Mo 1988). In this case, the right to consent extends to the right to refuse; in *In re Estate of Brooks* 32 Ill 2d 361, 205 NE 2d 435 (1965) it was held that even if the decision is foolish, the refusal has to be respected. The same pronouncement was made in *Re Yetter* 62 Pa D & C 2d 619 (1973). In *Brophy* 497 NE 2d 626 (Mass 1986) the right to self determination, human dignity is the basis for informed consent to medical treatment and consequently the right to refuse medical treatment. The recognition of treatment refusal arose from informed consent, also in *Matter of Guardianship of LW* 482 NW 2d 60 (Wis 1992).

[38] For example, in *Chatterton v Gerson & Anor* [1981] QB 432 Bristow J found that "there is no obligation on the doctor to canvass with the patient anything other than the inherent implications of the particular operation he intends to carry out. The fundamental assumption is that he knows his job and will do it properly. But he ought to warn of what may happen by misfortune however well the operation is done."

[39] See Jonathan F Will "A Brief Historical and Theoretical Perspective on Patient Autonomy and Medical Decision Making Part II: The Autonomy Model" (June 2011) 139(6) Chest 1491.

[40] Ian Dowbiggin *A Concise History of Euthanasia: Life, Death, God and Medicine* (Rowman & Littlefield Publishers, Inc., USA, 2005) at 124.

[41] *In The Matter of Karen Quinlan, An Alleged Incompetent* 355 A 2d 647 (NJ 1976).

law right to refuse treatment constituted the right of privacy which ought to be respected. The New Jersey Supreme Court granted declaratory relief to Quinlan's father, allowing the removal of the ventilator, with no criminal liability attached to the doctors. Cases after *Quinlan* confirmed the right to refuse treatment as an expression of autonomy.[42]

In respect of treatment refusal in advance and the concept of living will as it was then known, clear and convincing evidence was required. No such evidence existed in the case of Nancy Beth Cruzan[43] who was injured in a car accident. The Supreme Court of Missouri required clear and convincing evidence that Nancy would have wanted life support to be terminated in a persistent vegetative condition, failing which the life support should be continued. In the absence of a living will, the brief remarks made by Nancy to her housemates prior to the accident were insufficient to constitute clear and convincing evidence of her intention. This decision was affirmed by the US Supreme Court on appeal. The request to produce clear and convincing evidence is suggestive of some resistance towards AD as a binding expression of treatment refusal. Additionally, the case revealed the difficulties faced by doctors and the courts in determining the existence of a valid expression of AD intended to govern future treatment.

The *Quinlan* decision was said to have "inspired the first US state law granting legal status to living wills."[44] Legislation started developing across the country, designed to give effect to patients' anticipatory decisions in the form of 'living will' statutes, as it was then known. Subsequent developments involved legislation permitting a patient to appoint an agent, or healthcare proxy, to make treatment decisions on the patient's behalf after the onset of incompetence. A species of hybrid statute then began to appear combining the two forms, living will and durable powers of attorney.[45] Together these developments have come to be known as 'advance directives.'[46] Although this was the generally accepted concept of ADs, I have adopted a definition of ADs that differs from this concept for the reasons stated in Chap. 1. The second generation definition includes the creation of durable powers of attorney followed by a third generation combining living wills and proxy decision maker.[47] Almost 22 states in the US had recognised ADs by 1984 and more than double that number by 1993.[48]

The right to refuse treatment applies to individuals who are mentally competent to consent, and this includes Jehovah's Witnesses. However, a Jehovah's Witness's

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[42] *Saikewicz* 370 NE 2d 417 (Mass 1977); *re Brown* 478 So 2d 1033 (Miss 1985); *Brophy* 497 NE 2d 626 (Mass 1986) and *Cruzan* 497 US 261 (1990).

[43] *Cruzan v Director, Missouri Department of Health* 497 US 261 (1990).

[44] The Encyclopaedia of Bioethics (Revised ed, 1995) vol 1 Warren Thomas Reich, at [573].

[45] Kennedy and Grubb *Medical Law* (3rd ed, Butterworths, London, 2000) at 2043.

[46] Ibid.

[47] Ibid., at 2047.

[48] "Chronology of Assisted Dying" (2013) Death with Dignity National Center. http://www.deathwithdignity.org/historyfacts/chronology. Accessed 19 June 2017.

refusal of blood transfusion is often controversial,[49] and especially contentious when played out before the courts. ADs provided Jehovah's Witnesses with the opportunity to rely on them to decline blood transfusions. While Jehovah's Witnesses intended their ADs to be binding, it has not necessarily been viewed as such by some courts,[50] although some have recognised the binding nature of ADs.[51] For Jehovah's Witnesses, ADs refusing blood transfusion signified a respect for their autonomy and religious belief, but such refusals have always been troubling, both in cases involving adults and children. This is because there are questions about whether the refusal is genuine.[52]

The legal developments from the US illustrate a gradual shift towards patient-centred decision-making, pointing to a growing recognition of patient autonomy through the idea of ADs. More often than not, medical negligence suits provide the first glimpse into the transformation that occurred in the doctor-patient relationship, which illustrate a challenge to a doctor's authority.[53] Although medico-legal cases occurred, the medical profession continued to operate generally in a paternalistic manner,[54] supported by the judiciary adopting the medical profession's standard

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[49] It was reported that the leaders of Jehovah's Witnesses have taken a less stringent approach towards refusal of blood transfusion following a long standing controversial ruling that Jehovah's Witnesses faced rejection from the faith if they received blood transfusion. While the leaders maintained that receiving blood is contrary to the tenets of the Jehovah's Witness faith, this act does not automatically expel them from being a member of the faith: Jane Little "Jehovah's Witnesses drop transfusion ban" *BBC* (UK, Wednesday, 14 June 2000). http://news.bbc.co.uk/1/hi/world/790967.stm. Accessed 8 October 2017.

[50] For example, the English Courts have declined to uphold the ADs refusing blood transfusions in *Re T* [1992] EWCA Civ 18; *HE v A Hospital NHS Trust & AE* [2003] EWHC 1017 (Fam); *NHS Trust v T (adult patient: refusal of medical treatment)* [2004] EWHC 1279 (Fam). These cases will be considered in Chap. 4.

[51] For example, *Malette v Shulman* (1990) 72 OR (2d) 417 is an example of the authoritativeness and binding nature of an AD refusing blood transfusion. In this case, the Ontario Court of Appeal upheld the patient's no blood transfusion card as binding on the doctor. This case will be explored further in Chapter 4. Other recent cases include *Newcastle upon Tyne Hospitals Foundation Trust v LM* [2014] EWCOP 454; *Nottinghamshire Healthcare NHS Trust v RC* [2014] EWCOP 1317.

[52] See for example, *Re T* [1992] EWCA Civ 18 and *X v The Sydney Children's Hospitals Network* [2013] NSWCA 320 involving a child of Jehovah Witness belief, the refusal was questionable as there was never really an autonomous decision because the child has been cocooned in faith.

[53] *Slater v Baker & Stapleton* (1767) 2 Wils 359, 95 ER 860 (KB). This is an early reported decision on medical negligence where patient consent was lacking in surgical procedures using experimental devices.

[54] A small exception to the prevalent paternalistic medical practices can be found in the earliest reported medical negligence decision on the patient's right to consent in *Slater v Baker & Stapleton* (1767) 2 Wils 359, 95 ER 860 (KB) in England in 1767. Although Slater was a case of medical negligence, which concerned surgeons who, without obtaining the patient's consent, rearranged the patient's femoral fracture using experimental devices it nonetheless provided early indications of challenging physicians' medical authority. See Tom O'Shea "Consent in History, Theory and Practice" Essex Autonomy Project Green Paper Report (University of Essex: Essex Autonomy Project, 2011). http://autonomy.essex.ac.uk/consent-in-history-theory-and-practice. Accessed 10 March 2017.

of care rather than a patient oriented standard of care.[55] This however changed following *Chester v Afshar*[56] and the recent case of *Montgomery v Lanarkshire Health Board (Scotland)*[57] where patients are now widely regarded as persons holding rights rather than as passive recipients of the care of the medical profession. The case showed the gradual recognition of the importance of personal autonomy, and that in making a decision which might have a profound effect on her health and wellbeing, a patient was entitled to information and advice about possible alternative treatments. Similarly in New Zealand, Rights 6 and 7 of the Code of Rights 1996 give every patient the right to be fully informed and the right to make an informed choice and give informed consent. These seminal sources changed the doctor-centric approach, one of beneficent or medical paternalism, to an empowered patient, granting patients rights to inquire into the obligations of doctors.

Cases that occurred in Australia established a patient centric approach in the disclosure of information and consent to treatment, for example, the decision in *Whitaker*[58] rejected the doctor-centred approach in the English decision in *Bolam*.[59] The gradual changes in the doctor-patient relationship described above underlie an important value, which is respecting patient autonomy, in the sense that the patient is the ultimate decision-maker, making decisions that are consistent with his or her own interpretation of wellbeing, even if it conflicts with clinical recommendations and results which are detrimental to the patient, to the extent of death.[60] The continuous support for the right-to-die, together with several highly-profiled withdrawals of treatment disputes consolidated the patient self-determination concept. The beneficence model characterised by physician superiority and patient obedience eventually gave way to the patient autonomy model when the law imposed the requirement of informed consent, both in receiving and refusing treatment.[61] These concepts, despite being couched in the rights language, do not permit individuals to demand treatment against doctor's professional ethics. Despite the recognition of patient autonomy, ADs were not seen as binding compared to contemporaneous treatment refusal.

The development of ADs is not limited to the United States.[62] In England and Wales, living wills started emerging when the Voluntary Euthanasia Society started

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[55] *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 583 (QB); *Sidaway v Bethlem Royal Hospital Governors and others* [1985] 1 AC 871(HL).

[56] *Chester v Afshar* [2004] UKHL 41.

[57] *Montgomery (Appellant) v Lanarkshire Health Board (Respondent) (Scotland)* [2015] UKSC 11.

[58] *Rogers v Whitaker* (1992) 175 CLR 479 (HCA).

[59] *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582 (QB) was endorsed in *Maynard v West Midlands Regional Health Authority* [1984] 1 WLR 634 (HL) and *Sidaway v Bethlem Royal Hospital Governors and others* [1985] 1 AC 871 (HL), but re-examined in *Bolitho v City and Hackney Health Authority* [1992] 13 BMLR 111 (CA).

[60] Jonathan F Will "A Brief Historical and Theoretical Perspective on Patient Autonomy and Medical Decision Making" (June 2011) 139(6) Chest 1491. Ruth R Faden and Tom L Beauchamp *A History and Theory of Informed Consent* (Oxford University Press, New York, Oxford, 1986) at 86.

[61] Jonathan F Will "A Brief Historical and Theoretical Perspective on Patient Autonomy and Medical Decision Making" (March 2011) 139 (3) Chest 669.

[62] Kennedy and Grubb *Medical Law* (3rd ed, Butterworths, London, 2000) at 2047.

distributing them in the 1970s.[63] Then the possibility of living wills was more seriously considered in the 1980s, following their popularity in the US.[64] The Report of the Working Party of Age Concern England and the Centre of Medical Law and Ethics, King's College, London considered the advantages and disadvantages of living wills.[65] This Report was published prior to the enactment of the Mental Capacity Act 2005. The Report arose in response to concerns about respecting an individual's wish, expressed while the individual is competent, to refuse life sustaining treatment in the event the individual become incompetent in the future and its legal position.[66] The Report was intended to discuss the range of options available to the UK, particularly on the feasibility of legislating laws governing ADs with reference to the developments in the United States. Common law cases soon developed, such as *Re T*[67] in 1992 and *Re C*[68] in 1994 in which the validity and binding status of the patients' ADs were considered. In *Re T* the English court established that a clear and applicable AD binds a doctor, while in *Re C* a prison inmate's refusal to amputate his leg was upheld to bind the doctors in the future.

In the absence of statute governing ADs in England and Wales at that time, judicial decisions that came before the courts provided some piecemeal guidance on the legal status of ADs. It was accepted that a mentally competent person has the right to refuse treatment, or to consent to the withdrawal of treatment.[69] The British Medical Association (BMA) responded to the issue of ADs with the publication of a guidance regarding ADs.[70] The BMA recognised the use of advance decisions and accepted that they could legally bind healthcare professionals if they were clear, applicable to the circumstances and voluntarily made by an informed competent person.[71] However, the BMA described advance decisions as a "general term covering a range of options which in the past were known as 'advance statements'."[72] The first English statute governing ADs, the Mental Capacity Act, was passed in 2005 and came into force in 2007.

The right to refuse treatment was accepted and applied in Australia.[73] The principle of self determination, as endorsed in the United States case of *Schloendorff v the*

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[63] CY Hong, LG Goh and HP Lee "The Advance Directive—A Review" (1996) 37 Singapore Med J 411 at 412.

[64] Age Concern Institute of Gerontology and Centre of Medical Law and Ethics *The Living Will: Consent to Treatment at the End of Life; A Working Party Report* (Edward Arnold, 1988) at 48.

[65] Ibid.

[66] Ibid., at 1–3.

[67] *Re T (adult: refusal of medical treatment)* [1992] EWCA Civ 18.

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

[69] *Airedale NHS Trust v Bland* [1993] AC 789; *Re JT (Adult: Refusal of Medical Treatment)* [1998] 1 FLR 48 and *Re AK (Medical Treatment: Consent)* [2001] FLR 129.

[70] British Medical Association "Advance Decisions and Proxy Decision-making in Medical Treatment and Research: Guidance from the BMA's Medical Ethics Department" (BMA, 2007).

[71] Ibid., at 2, 3.

[72] Ibid., at 2.

[73] Ben White, Fiona McDonald and Lindy Willmott *Health Law in Australia*, (Thomson Reuters (Professional) Australia Ltd., NSW, 2010) at 94.

Society of the New York Hospital in 1914, was approved by the High Court of Australia in *Secretary, Department of Health and Community Services (NT) v JWB and SMB (Marion's case).*[74] The right to refuse treatment in an AD was legally adopted in *Hunter and New England Area Health Service v A*[75] in New South Wales. Most of the Australian jurisdictions have recognised ADs in their legislation, except for New South Wales and Tasmania where the common law continues to apply in the absence of statutory provisions.[76]

Canada has also recognised the common law right to refuse consent to treatment.[77] The seminal 1990 Canadian decision, *Malette v Shulman* on refusing a blood transfusion came about when Mrs. Malette successfully sued Dr. Shulman for transfusing blood against her Jehovah's Witness belief, recognising the primacy of personal autonomy.[78] Cases after Malette such as *Rodriguez v British Columbia (Attorney General)*[79] and *Ciarlariello v Schacter*[80] confirmed the right to consent to and refuse treatment.

Recent developments in ADs include the promotion of advance care planning (ACP), which entails a process of discussing future care plans, and extends beyond medical treatment. Other examples of advance care planning initiatives include the Respecting Choices® Programme,[81] which encourages conversations between the caregiver and the person facing changing end-of-life situations about that person's preferences and expectations, which then influences the direction of care and quality of life.[82] Advance care planning thus shares the same goal as ADs, that of promoting individuals to plan for their future based on the principle of autonomy. This practice became popular in the United States, some European countries, Canada and Australia,

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[74] *Secretary, Department of Health and Community Services (NT) v JWB and SMB (Marion's case)* [1992] 175 CLR 218.

[75] *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88.

[76] Ben White, Fiona McDonald and Lindy Willmott *Health Law in Australia* (Thomson Reuters (Professional) Australia Ltd., NSW, 2010) at 94, 158.

[77] Jocelyn Downie "Assisted Death at the Supreme Court of Canada," in Jocelyn Downie and Elaine Gibson (eds) *Health Law at the Supreme Court of Canada* (Irwin Law, Toronto, 2007) 219 at 232, 233–234.

[78] *Malette v Shulman* [1990] 67 DLR (4th) 321.

[79] *Rodriguez v British Columbia (Attorney General)* [1993] 3 SCR 519, the majority of the Supreme Court of Canada embraced key lower court withholding and withdrawal cases at 598: "Canadian courts have recognised a common law right of patients to refuse consent to medical treatment or to demand that treatment, once commenced, be withdrawn or discontinued. This right has been specifically recognised to exist even if the withdrawal from or refusal of treatment may result in death."

[80] *Ciarlariello v Schacter* [1993] 2 SCR 119 was a case involving a woman who changed her mind in the middle of a procedure (an angiogram) and while having originally consented, cried out "enough, no more, stop the test." It provides a clear and broad statement on the Supreme Court of Canada's view of refusals of treatment. The Supreme Court at 135 stated that "it should not be forgotten that every patient has a right to bodily integrity."

[81] www.advancecareplanning.org.au.

[82] Keri Thomas and Ben Lobo (eds) *Advance Care Planning in End of Life Care* (Oxford University Press, Oxford, 2011) at 4.

even where statutory laws exist.[83] In England and Wales, AD and ACP programmes were rolled out in response to implementing the Mental Capacity Act 2005.[84]

The value of ACP lies in its potential for promoting patient involvement in decision-making,[85] although it is unclear what type of decision-making process is contemplated in an ACP discussion, or what would be the legal status of such plans once they are being made. It is possible that discussions carried out in an ACP conversation may be taken into account by proxy decision-makers when a treatment decision is required. These discussions may also turn into written ADs if the person wants to record such treatment wishes. Nonetheless, these ACP practices are silent on whether such completed advance care plans bind healthcare professionals when they are called into implementation or where questions are raised regarding the circumstances under which these wishes are made. This seems to suggest that ACP practices, while valuable as an initiation of discussion for future treatment, lacks qualities that render them reliable, unlike contemporaneous refusals.

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[83] For example, End of Life Care Strategy published by the National Health Services (NHS), Gold Standards Framework (GSF). https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life https://www.nhs.uk/Planners/end-of-life-care/Pages/advance-decision-to-refuse-treatment.aspx. Accessed 18 October 2017; Dying Matters Coalition. www.dyingmatters.org. Australia, Respecting Patient Choices Programme (RPCS), National Framework for Advance Care Directives (September 2011) Australian Health Ministers' Advisory Council at http://www.coaghealthcouncil.gov.au/Publications/Reports. Accessed 9 November 2017; Canada, Speak Up. www.advancecareplanning.ca. MyVoice: Expressing my wishes for future healthcare treatment, Advance Care Planning Guide. http://www.health.gov.bc.ca/library/publications/year/2013/MyVoice-AdvanceCarePlanningGuide.pdf. Accessed 9 November 2017; National POLST Paradigm, USA, Physician Order for Life Sustaining Treatment (POLST). http://polst.org/advance-care-planning/polst-and-advance-directives/. Accessed 8 November 2017; New York State Department of Health, Medical Order for Life Sustaining Treatment (MOLST). https://www.health.ny.gov/professionals/patients/patient_rights/molst/. Accessed 9 November 2017; National Healthcare Decisions Day. https://www.nhdd.org/#welcome. Accessed 7 November 2017; www.mylifedirective.org; www.compassionandsupport.org; https://www.agingwithdignity.org.

[84] The Department of Constitutional Affairs, the NHS, Department of Health, the Public Guardian Office and the Mental Capacity Implementation Programme has published various toolkits designed to ensure that the Mental Capacity Act and the Code of Practice is operationalised to the public, social worker, caregivers, doctors and nurses. The various publications are: UK ADRT Support Sheet and Fact Sheet, the Making Decision series which include Making Decisions: A Guide for People who Work in Health and Social Care (National Care Association, Mental Capacity Implementation Programme, 2009, OPG603), Making Decisions: The Independent Mental Capacity Advocate (IMCA) Service, written by Sue Lee of Speaking Up, 2007; Making Decision: About your health, welfare or finances, who decides when you can't (2009) Turning Point, Scope and Mind who are members of the Making Decisions Alliance; Making Decisions: A Guide for Family, Friends and Unpaid Carers (2007) Turning Point, Sense, Alzheimers Society, Age Concern; Making Decisions: A Guide for Advice Workers, OPG604, 2009.

[85] Nancy Freeborne, Joanne Lynn and Norman A Desbiens "Insights about dying from the SUPPORT Project" (2000) 48(5) Journal of the American Geriatrics Society S199. In the study, the authors found that ADs were introduced at a later stage of terminal illness when the patient has become unable to participate effectively in expressing their wishes. They suggested that there is room for advance care planning at an earlier stage before incapacity takes place, which should be helpful towards improving care condition in patients who are terminally ill.

Despite its importance, there is a lack of universal definition of ACP, until recently, where it was broadly agreed as "the ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate."[86] The consensus was reached by a group of renowned panel experts with clinical and research experience in disciplines of palliative care, geriatrics and ethics tasked with building "a systematic consensus on ACP".[87] The panel experts, commissioned by the European Association for Palliative Care Board recommended improved and targeted use of ACP according to the person's health conditions, in addition to using trained facilitators who are not doctors in supporting the discussion process.[88]

The experts similarly highlighted the significance of the timing in engaging in the ACP process, which could be challenging to providing care if it is carried out too early or too late to be of use. Most significantly, recommendations that received strong support in the area of regulating ACP is the option of having ADs in both structured and open-ended formats, together with a support system in healthcare services where ADs are available to be accessed when they are needed. They also lobbied for laws to recognise the binding nature of the outcome arising from the advance care planning process.[89]

ADs have come a long way since they began to appear as part of the euthanasia movement. They then evolved into an important mechanism in healthcare decision-making as the decades unfolded, with the recognition of the right to refuse treatment as an expression of personal autonomy in the legal sphere. They continue to be contentious, as there are on-going debates about their legal status, unlike contemporaneous refusals. There had been cases where patients and families took to the courts to obtain remedies for healthcare providers' refusal to honour ADs; but without much successful outcomes.[90] Thus far the development of ADs illustrates an emergence in patient autonomy, against a paternalistic background, guided by the beneficence

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[86] *Judith A C Rietjens, Rebecca L Sudore, Michael Connolly, Johannes J van Delden, Margaret A Drickamer, Mirjam Droger, Agnes van der Heide, Daren K Heyland, Dirk Houttekier, Daisy J A Janssen, Luciano Orsi, Sheila Payne, Jane Seymour, Ralf J Jox, Ida J Korfage, on behalf of the European Association for Palliative Care* Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care (2017) 18 *Lancet Oncol* e543–51.

[87] Ibid.

[88] Ibid. at 543.

[89] Ibid. at 546.

[90] *Anderson v St. Francis-St. George Hosp., Inc.* 671 NE 2d 225 (Ohio 1996); *McGuiness v Barnes No. A-3457-94T5* (NJ Supr Ct App Div (1996); further see the commentaries in Adam Milani "Better off Dead than Disabled? Should courts recognise a 'wrongful living' cause of action when doctors fail to honor patient's advance directives?" (1997) Wash & Lee L Rev 149; Daniel Pollack, Chaim Steinmetz and Vicki Lens "*Anderson v St. Francis-St. George Hospital*: Wrongful Living from an American and Jewish Legal Perspectives" (1997) 45 Cleveland State Law Review 621; Philip G Peters Jr "The Illusion of Autonomy at the End of Life: Unconsented Life Support and the Wrongful Life Analogy" (1998) 45 UCLA Law Review 673; Colin Gavaghan "Anticipatory Refusals and the action of wrongful living" (2000) 5 Medical Law International 67; Holly Fernandez Lynch, Michele Mathes and Nadia N Sawicki "Compliance With Advance Directives: Wrongful Living and Tort Law Incentives" (2008) 2 J Legal Medicine 29.

model within the therapeutic relationship. How does autonomy feature in medical law generally? The next section considers this point.

2.1.2 Autonomy in Medical Law and Advance Directives

Autonomy is accepted in medical law as an important, valuable ethical principle and vital for the wellbeing of humans.[91] Willmott, White and Mathews appropriately recognised that autonomy has progressed naturally as a liberal democratic society developed.[92] Autonomy, in the context of medical law is really concerned with *negative* autonomy. Doctors cannot generally treat patients without the patient's informed consent and patients have the right to decline treatments. Their right to refuse treatment even extends to treatment that their doctors are utterly convinced will benefit them. For example, Ms S in *St George's*[93] won her right to refuse treatment, even though both she and her unborn child were at risk of dying without medical intervention. The English Court of Appeal affirmed her autonomy against the medical judgement of her doctors. Autonomy thus implies a meaning where individuals are not to be treated without their consent, a type of autonomy that adopted John Stuart Mill's understanding of non-interference or the negative rights. That means that if I do not consent to you touching me or treating me, you are restricted from doing so. However, there are limits to autonomy in order to protect other people from harm such as quarantine laws affecting public health or compulsory treatment for patients suffering from mental disorders that posed as dangers to society.[94] But in the absence of such exceptions, autonomy is dominant, and has been accepted as the justification for contemporaneous refusal.

The right to decline treatment does not translate into a right to *demand* treatment or, as Brazier puts it, "demand unthinking deference to any choice made by another human being."[95] An example is the English decision of *Burke*.[96] Mr. Burke was a 45-year-old man who suffered from a congenital degenerative brain condition resulting

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[91] Marina Oshana *Personal Autonomy in Society* (Ashgate Publishing Ltd., England, 2006); Tom L Beauchamp and James F Childress *Principles of Biomedical Ethics* (7th ed, Oxford University Press, New York, Oxford, 2013).

[92] Lindy Willmott, Ben White and Ben Mathews "Law, Autonomy and Advance Directives" 2010 (18) Journal of Law and Medicine 366.

[93] *St George's Healthcare NHS Trust v S* [1998] 3 WLR 936 (CA).

[94] Other examples of exceptions to patient autonomy in the United States are broadly premised on consideration for other parties' rights, most notably preventing suicide and maintaining the professional and ethical integrity of the medical professionals: See Anne Falmme and Heidi Forster "Legal limits: when does autonomy in health care prevail?" in Michael Freeman and Andrew Lewis (eds) *Law and Medicine: Current Legal Issues vol. 3* (Oxford University Press, US, 2000) at 156.

[95] Margaret Brazier *Medicine, Patients and the Law* (3rd ed, Penguin Group, England, 2003) at 39.

[96] *R (on the application of Oliver Leslie Burke) v The General Medical Council, The Disability Rights Commission, The Official Solicitor to the Supreme Court* [2004] EWHC 1879 (Admin).

in severe physical disabilities.[97] The condition would lead him to fully depend on the others for his survival, especially his ability to swallow, which would require feeding through tube.[98] He wanted feeding until he died and sought the court's declaration that it would be unlawful for the hospital to withhold or withdraw artificial nutrition and hydration before he died.[99] In the High Court Munby J ordered the hospital to comply with Mr. Burke's request to have continued hydration and nutrition until he died of natural causes. Failure to do so would breach his personal autonomy and human rights. Munby J also invalidated several provisions in the General Medical Council's (GMC) guidelines which provides for withholding and withdrawing life prolonging treatment "without prior judicial authorisation".[100] In this respect, Munby J saw the fight to *demand* treatment as being the logical corollary of the well-recognised right to *refuse* treatment.[101]

This decision was unanimously overturned by the Court of Appeal on appeal by the GMC.[102] The Court of Appeal declared that the patient has a right to refuse treatment options offered, but it was not open to the patient to insist on receiving specific treatment.[103] The Court of Appeal forcefully rejected the interpretation of Munby J, citing that "Autonomy and the right of self-determination do not entitle the patient to insist on receiving a particular medical treatment regardless of the nature of the treatment."[104]

New Zealand courts too have accepted autonomy as the predominant principle, but they also tend to draw the line when it comes to demands for treatment. The *Shortland v Northland Health Ltd.* decision is another example of a patient's demand for treatment being declined. The New Zealand Court of Appeal upheld the hospital's decision to discontinue with dialysis treatment to Mr. Williams because that was consistent with good medical practice.[105]

Although the notion of autonomy as understood in medical law is mostly seen in negative terms, a more limited positive dimension has been recognised. For example, Article 2 of the European Court of Human Rights recognises "Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally". A limited common law duty to rescue has been recognised for doctors.[106] Autonomy

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[97] Ibid., at [3].

[98] Ibid., at [4].

[99] Ibid., at [6], [24].

[100] Ibid., at [225].

[101] Ibid., at [166].

[102] *Burke v The General Medical Council, The Disability Rights Commission and others* [2005] EWCA Civ 1003.

[103] Ibid., at [51] per Lord Phillips MR.

[104] Ibid., at [31].

[105] *Shortland v Northland Health Ltd.* [1998] 1 NZLR 433 (CA).

[106] *Lowns v Woods* by his next friend the Protective Commissioner and Ors [1996] Aust Torts Reports 81 (NSW CA).

has come to hold such a prominent position in medical law and ethics.[107] The case for and against ADs have been controversial in medical treatment. We take a look at the ADs debate in the following section.

2.2 The Advance Directives Debate

There are two broad themes in the AD debate. One theme critiqued the moral authority of ADs[108] while the other questioned the legal validity of the written directive.[109] Probing further within the debate, there were strong arguments in advancing and rejecting ADs.[110] Among bioethicists, there emerge differing views concerning the authority of ADs as an effective end-of-life decision-making instrument. Scholars in favour of ADs[111] welcome ADs as a means of protecting the right

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[107] We will see that the conventional understanding of autonomy would not necessarily apply to ADs. This notion will be explored in Chap. 4 where I consider the supported decision-making approach in ADs.

[108] Thomas May "Reassessing the Reliability of Advance Directives" (1997) 6 Cambridge Quarterly of Healthcare Ethics 325; John K Davis "Precedent Autonomy and Subsequent Consent" (June 2004) 7 Ethical Theory and Moral Practice 267.

[109] See for example Cameron Stewart "Advance Directives: Disputes and Dilemmas" in Ian Freckelton and Kerry Petersen (eds) *Disputes and Dilemma in Health Law* (The Federation Press, Australia, 2006); Thomas A Faunce and Cameron Stewart "The *Messiha* and *Schiavo* cases: third-party ethical and legal interventions in futile care disputes" (2005) 183 MJA 261; M Parker and others "Two steps forward, one step back: advance care planning, Australian regulatory frameworks and the Australian Medical Association" (2007) 37 Internal Medicine Journal 637; Sheila McLean "Advance Directives: Legal and Ethical Considerations" in N Pace and S McLean (eds) *Ethics and the Law in Intensive Care* (OUP, Oxford, 1996); Colin Gavaghan "Trial of wills—to sue or not to sue" vol. 18 number 3 (1998) 18 VESS Newsletter; Colin Gavaghan "Anticipatory Refusals and the action of wrongful living" (2000) 5 Medical Law International 67.

[110] Cees MPM Hertogh "The Misleading Simplicity of Advance Directive" (2011) 23 International Psychogeriatrics 511 (the author questioned whether advance directive is the answer to the problems it set out to solve); see also A Sommerville "Are Advance directives really the answer? And what was the question?" in Sheila AM McLean Death, Dying and the Law (Dartmouth, Aldershot, 1996) at 40–46; JA Devereux Australian Medical Law (3rd ed, Routledge Cavendish, 2007) at 933–938 who questioned the perceived benefits of advance directive; Christopher Buford "Advancing An Advance Directive Debate" (2008) 22 Bioethics 423.

[111] An example is an investigative study which supported the continued use of advance directives in elderly patients who had prepared advance directives received care that was strongly associated with their preferences; see Silveira MJ, Kim SY and Langa KM "Advance directives and outcomes of surrogate decision-making before death" (2010) 362 N Engl J Med 1211; Norman L Cantor "Advance Directive Instruments for End-Of-Life and Health Care Decision Making: Making Advance Directives Meaningful" (1998) 4 Psych Pub Pol and L 629; Jeffrey Blustein "Choosing for Others as Continuing a Life Story: The Problem of Personal Identity Revisited" (1999) 27 Journal of Law, Medicine & Ethics 20; Mark G Kuczewski "Whose Will Is It, Anyway? A Discussion of Advance Directives, Personal Identity, and Consensus in Medical Ethics" (1994) 8 Bioethics 27; Michael Quante "Precedent Autonomy and Personal Identity" (1991) 9 Kennedy Institute of Ethics Journal 365; Peter A Singer "Advance directives: Are they an advance?" (1992) 146 Can Med Assoc J 127.

to make decisions, while the critiques[112] argue that the directive loses its authority as the maker becomes incompetent and more fundamentally attack the concept of ADs as being flawed.[113] In refuting scepticism towards ADs, the advocates for ADs have advanced the 'narrative theory' so as to defend the authority of ADs from failing for want of psychological continuity[114] while another view suggested that personal identity is immaterial.[115] These debates illustrate the contentious nature of ADs as expressions of personal autonomy and the difficulties in being accepted as legally binding at the implementation stage. It is significant to examine the original justification for AD, as proposed by Luis Kutner.

2.2.1 Autonomy, Privacy and Trust

ADs lie at the crossroads between the availability of life-prolonging treatment and the ability to refuse life-prolonging treatment. Luis Kutner, the founder and advocate of living wills[116] coined the term "living will". It is referred to as "living" because it governs the living person and "will" because the instructions relate to dying. The surge of interest in the euthanasia discussion provided the impetus to further exploration of ADs as an avenue to exercise an individual's autonomy. Kutner's inspiration for ADs arose from the dilemma in euthanasia in the context of criminal law and the state's obligation to protect life.[117] His idea stemmed from the criminality of suicide and euthanasia. He illustrated two decisions to support his claim. The first case was Robert Waskin, (which we saw in Chap. 1) who shot his cancer stricken mother to death in 1967, demonstrating the common law's weaknesses in not recognising motive as an element of homicide in crime law. His act in shooting his mother was

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[112] Angela Fagerlin and Carl E Schneider "Enough: The Failure of the Living Will" (2004) Hasting Center Report 30; Rebecca Dresser "Advance Directives Implications for Policy" (Nov.–Dec., 1994) 24 The Hastings Center Report S2-S5; John K Davis "Precedent Autonomy and Subsequent Consent" (June 2004) 7 Ethical Theory and Moral Practice 267; Allen Buchanan "Advance Directives and the Personal Identity Problem" (1988) 17 Philosophy and Public Affairs 277.

[113] Henry S Perkins "Controlling Death: The False Promise of Advance Directives" (2007) 147 Annals of Internal Medicine 51; Christopher James Ryan "Betting your life: an argument against certain advance directives" (1996) 22 Journal of Medical Ethics 95; Angus Dawson and Anthony Wrigley "A Dead Proposal: Levi and Green on Advance Directives" (2010) 10 The American Journal of Bioethics 23; Anthony Wrigley "Personal Identity, Autonomy and Advance Statements" (2007) 24 Journal of Applied Philosophy 381; Steven B Hardin and Yasmin A Yusufaly "Difficult End-of-Life Treatment Decisions: Do Other Factors Trump Advance Directives?" (2004) 164 Arch Intern Med 1531.

[114] Jeffrey Blustein "Choosing for Others as Continuing a Life Story: The Problem of Personal Identity Revisited" (1999) 27 Journal of Law, Medicine & Ethics 20.

[115] David Shoemaker "The Insignificance of Personal Identity for Bioethics" (2010) 24 Bioethics 481.

[116] Luis Kutner "Due Process of Euthanasia: The Living Will: A Proposal" (1968–1969) 44 Ind L J 539.

[117] Ibid.

motivated by compassion, watching the mother suffering from the effects of cancer. Secondly, he referred to the predicament of a 69-year-old man who suffocated his “crippled, bedridden arthritic” wife.[118] The court found him not guilty, having accepted the evidence that he had been caring unfailingly for his wife over a period of two years, in addition to the doctor’s testimony that the wife was in constant agonising pain and mental despair.

Kutner reasoned that the two decisions signified that courts treated mercy killing differently from other murder cases. In the Robert Waskin example the courts circumvented the consequences of a murder conviction by finding the defendant not guilty by virtue of insanity. Kutner pointed out that the law on euthanasia left much to be desired and the absence of at least a semblance of objective determination of intent was a gap in the legal system.[119] Having identified the dissatisfactory state of criminal law regarding euthanasia and murder, Kutner proceeded to make a case for living wills, justifying them on three main grounds—the right to privacy under the United States constitution, the right to self-determination and the concept of revocable trust.

For the first justification, Kutner argued that the failure to recognise the right to die as desired was an infringement of the individual’s right of privacy protected under the United States Constitution.[120] He reasoned that, in protecting the right to privacy under the United States Constitution, and based on the principle that a person must not be treated without his consent, a person, while retaining full capacity, could give or refuse consent to treatment in the event that he loses the ability to express his wishes at an unanticipated time.[121] That proposal created an exception to the general presumption of ‘constructive consent’ to life-saving treatment when a person is unconscious or is not in a position to give his consent. The question then is as to how far such constructive consent should extend.[122]

The law recognised a person’s right to refuse treatment; a person retained the right of privacy over his body when there was a possibility that he would be “kept in a state of indefinite vegetated animation.”[123] Kutner illustrated this point using two examples. First, a patient undergoing elective surgery or other radical treatment could sign a legal statement not only consenting to the treatment, but also stating that consent to further treatment would cease should the patient’s condition be incurable. Secondly, in the case of an emergency situation, for example, where a patient can become the victim of a sudden accident or a stroke or coronary. The safeguards he proposed were that the document be notarised and attested by at least two witnesses.[124] He explained that requiring affirmations that the person

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[118] Ibid., at 541.

[119] Luis Kutner “Due Process of Euthanasia: The Living Will: A Proposal” (1968–1969) 44 Ind L J 539 at 542.

[120] Ibid., at 543.

[121] Ibid., at 550, 551.

[122] Ibid., at 547.

[123] Ibid., at 550.

[124] Ibid., at 549–550.

is mentally competent and acting voluntarily through the act of notarisation and attestation is equivalent to a contemporaneous refusal.

In respect of the second justification, Kutner explained that self-determination is the privilege of mankind. As death was inevitable, a person had the right to "play a decisive role in making preparations for his own death."[125] As to the third justification, living wills are similar to the concept of revocable or conditional trust.[126] Pursuant to this concept, doctors became the trustees of the patient's body, while the patient was the grantor and the beneficiary of the trust.[127] The caveat for the use of living will was that it was not to be used to direct doctors to actively terminate the person's life, because a trust would not be upheld if the purpose was contrary to public policy.[128] Therefore, a living will that authorised euthanasia was contrary to the law's function in protecting life[129] consistent with the legal prohibition of mercy killing even if the patient consented to it. A living will could merely be used to refuse treatment or require its withdrawal.

Thus, Kutner had grounded his justifications for living wills on the basis of autonomy and the right to refuse treatment is extended to govern a situation of future incapacity. What Kutner did at that time was to advocate an alternative approach to governing treatment refusal in the future on the principle of autonomy, thus giving an option to patients to refuse unwanted life prolonging treatment when the person has become incompetent. Living wills that are completed and passed to a spouse, next of kin, confidante, family lawyer or attending doctors announce to those people the individual's intention to refuse treatment in the future, while personal possession of a living will would establish a presumption that the individual concerned regarded it as binding.[130] Although Kutner did not specifically address the question of Jehovah's Witnesses refusing blood transfusions, it can be inferred from his argument that the right to privacy would be equally applicable to them and granted constitutional protection.

The AD concept introduced by Kutner has been reinterpreted by scholars advocating the use of ADs. Nancy King, particularly, advocated ADs as a better means of decision-making compared to other forms of decision-making such as relying on substitute decision-makers because the patient has a strong and clear moral interest and legal right to act as the ultimate decision-maker, which extends to all decisions.[131] Having considered Kutner's arguments, I now turn to examine the opponents of Kutner's arguments for ADs and the range of arguments that can counter them.

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[125] Luis Kutner "The Living Will: Coping with the Historical Event of Death" (1975) 27 Baylor L Rev 39 at 41, 42.

[126] Luis Kutner "Due Process of Euthanasia: The Living Will: A Proposal" (1968–1969) 44 Ind L J 539 at 552.

[127] Ibid.

[128] Ibid., at 553.

[129] Ibid.

[130] Luis Kutner "The Living Will: Coping with the Historical Event of Death" (1975) 27 Baylor L Rev 39.

[131] Nancy M P King *Making Sense of Advance Directives* (Georgetown University Press, Washington DC, 1996) at 4.

2.2.2 *Utility and Conceptual Problems*

In this section, oppositions to ADs can be broadly classified into two—ADs are conceptually flawed and they are impractical to implement.

2.2.2.1 ADs Are Conceptually Flawed and Do not Represent the Autonomous Wishes of the Person

This contention challenged the core of the AD concept.[132] The challenge is significant, given that recent literature has focused on the moral and ethical issues of ADs in anticipating dementia and those diagnosed as minimally conscious.[133] They demonstrated an underpinning moral difficulty with making ADs in the most complicated cases. Critiques of ADs argued that respecting an AD harmed the current interest of the incompetent person, and would not necessarily promote the person's autonomy. According to this view, the approach towards treating an incompetent person should be based on the person's best interest rather than autonomy. This opposition is based on an underlying assumption that ADs are inherently flawed because of the philosophical concerns regarding its moral authority, and concerns about the continuity of personal identity between the present person and the person who made the AD previously.[134] According to this approach, a continued, unified identity is essential to personal identity, from which springs the validity of any preferences.[135]

The AD loses its authority when the person becomes incompetent. Although the person retains certain interests, the person who has now become incompetent no longer has the same interests as the person who made the AD previously. In this

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[132] Henry S Perkins "Controlling Death: The False Promise of Advance Directives" (2007) 147(1) Annals of Internal Medicine 51; Rebecca Dresser "Advance Directives Implications for Policy" (Nov.–Dec., 1994) 24(6) The Hastings Center Report S2.

[133] Stephen Napier "The Minimally Conscious State, the Disability Bias, and the Moral Authority of Advance Directives" (2018) International Journal of Law and Psychiatry. https://doi.org/10.1016/j.ijlp.2018.03.001; Barak Gaster, Eric B. Larson, and J. Randall Curtis "Advance Directives for Dementia: Meeting a Unique Challenge" (2017) 318(22) JAMA 2175; Keydron K Guinn and Charlotte R Winston "Advance directives and individuals with disabilities" (2018) 11 Disability and Health Journal 6; David Limbaugh "Animals, Advance Directives, and Prudence: Should We Let the Cheerfully Demented Die?" (2016) 2(4) Ethics, Medicine, and Public Health 481; Hilde Lindemann "Holding on to Edmund: The relational work of identity" in Lindeman H, Verkerk M, Walker MU (eds) *Naturalized Bioethics* (Cambridge University Press, Cambridge, 2009); Andrea Ott "Personal Identity and the Moral Authority of Advance Directives" (2009) 4(2) The Pluralist 38; Paul T Menzel "Voluntarily Stopping Eating and Drinking: A Normative Comparison with Refusing Lifesaving Treatment and Advance Directives" (2017) 45 The Journal of Law, Medicine & Ethics 634. https://doi.org/10.1177/1073110517750602.

[134] Thomas May "Reassessing the Reliability of Advance Directives" (1997) 6 Cambridge Quarterly of Healthcare Ethics 325; John K Davis "Precedent Autonomy and Subsequent Consent" (Jun., 2004) 7(3) Ethical Theory and Moral Practice 267.

[135] Rebecca Dresser "Dworkin on Dementia: Elegant Theory, Questionable Policy" (Nov.–Dec. 1995) 25(6) The Hastings Center Report 32; Rebecca Dresser "At Law: The Conscious Incompetent Patient" (May–Jun., 2002) 32(3) The Hastings Center Report 9.

sense, the AD does not bind the incompetent person because the incompetent person's needs and interests differ from the previously competent person.[136] This approach, which argued that there is a lack of continuity of self between the individual's current interest and previous wishes, has become known as "the stranger" contention. In this sense, the individual at the current state becomes a stranger to his or her old self, thus the old self's preferences would be inapplicable to the current self. The lack of continuity of identity thus challenged the person's autonomy, the normative force of the AD, and its application to the now incompetent person. This contention, when applied to a person with dementia, arguably implied that the AD would be equally weakened, thus creating doubt on the moral authority of the AD.[137] A second aspect is the "black box" argument, in which a person who has not experienced illness will feel differently about refusing treatment when they have experienced it. This implied that a person who had received treatment after refusing it initially would feel differently about their initial refusal.

Thomas May contended that an AD is similar to voluntary slavery because there is no opportunity to reconsider the decision should a change of mind occur once the person becomes incompetent.[138] He argued against treating ADs as equivalent to the decision made by a competent patient.[139] This is attributed to the difference between ADs and contemporaneous refusals, and because of this difference, an AD requires additional measures before it can be valid and applicable. One way to establish the reliability, for example, is by prior experience, consistency with other decision and discussion with doctors or psychologists. He reasoned that an autonomous decision must include an ability to reassess one's commitment to the strategy.[140] Tollefsen, in response to May, argued that ADs serve as an indication of the patient's preferences, thus allowing an extension of self-determination, preserving autonomy and identity simultaneously.[141] An AD preserves autonomy and identity with a future

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[136] Rebecca Dresser "Advance Directives Implications for Policy" (Nov.–Dec., 1994) 24(6) The Hastings Center Report S2, Angela Fagerlin and Carl E Schneider "Enough: The Failure of the Living Will," (March–April 2004) 2 Hastings Center Report 30 (although the authors are receptive towards the use of durable power of attorney and reject living wills); John K Davis "Precedent Autonomy and Subsequent Consent Ethical Theory and Moral Practice" (Jun., 2004) 7(3) The Hastings Center 267; Allen Buchanan "Advance Directives and the Personal Identity Problem" (Autumn, 1988) 17(4) Philosophy and Public Affairs 277.

[137] Andrea Ott "Personal Identity and the Moral Authority of Advance Directives" (2009) 4(2) The Pluralist 38. Dresser similarly addressed this point earlier in Rebecca Dresser "Dworkin on Dementia: Elegant Theory, Questionable Policy" (Nov.–Dec. 1995) 25(6) The Hastings Center Report 32.

[138] Thomas May "Reassessing the Reliability of Advance Directives" (1997) 6 Cambridge Quarterly of Healthcare Ethics 325.

[139] Ibid.

[140] Ibid.

[141] Christopher Tollefsen "Response to 'Reassessing the Reliability of Advance Directives' by Thomas May (6(5) CQ Advance Directives and Voluntary Slavery)" (1998) **7** Cambridge Quarterly of Healthcare Ethics 405.

self, regardless of the risks one assumes. Tonelli[142] similarly doubted AD's promise as continuing the exercise of autonomy when it was plagued with questions about the unresolved issue of personal identity of the patient, intention and the meaning of the AD as envisioned by the individual, in which case the AD cannot be accepted as binding without independent verification.

A strong philosophical response to the conceptual criticisms of ADs can be found in the 'narrative theory' of identity. This approach saves the authority of ADs from failing for want of psychological continuity.[143] The narrative theory views persons as authors of their life stories and sees proxies playing the role of continuing the life stories, thus rendering the personal identity argument immaterial to constitute the legitimacy of ADs. There will be no question about whether the person who makes the AD is the same person because the narrative theory treats the person as the same person whose life story is continually being 'written.' In addition, arguments have been put forward to suggest that cognitive impairments do not automatically invalidate personal identity and by implication the discontinuity of personal identity does not threaten the surviving interest inherent in persons who have become incompetent.[144] Nancy Rhoden persuasively advocated[145]:

> post-consciousness betrayals can count as wrongs to the person, viewed as she was when the promise was made, because the living have assumed a duty to view her as she was when alive or conscious and not as a mere corpse or insentient body.

This rests on the assumption that continuity of the self persists and pursuant to a rights-based approach justified honouring the person's AD. Rhoden hypothesised that if we accepted that the current interest prevails over the prior wishes, that means once a person becomes incompetent the person's directive will be ignored. She drew an analogy to Jehovah's Witness, in which case they have to bleed out for them to be eventually transfused.[146] In fact not only Jehovah's Witnesses, almost anyone who has ADs will have them disregarded once they lose consciousness or become incompetent. As King rightly observed, the conscious decision to make an AD gives

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[142] Mark R Tonelli "Pulling the Plug on Living Wills: A Critical Analysis of Advance Directives" (1996) 110 Chest 816.

[143] Jeffrey Blustein "Choosing for Others as Continuing a Life Story: The Problem of Personal Identity Revisited" (Spring 1999) 27(1) Journal of Law, Medicine & Ethics 20. Some however, held the view that personal identity is immaterial: David Shoemaker "The Insignificance of Personal Identity for Bioethics" (2010) 24(9) Bioethics 481.

[144] David Shoemaker "The Insignificance of Personal Identity for Bioethics" (2010) 24(9) Bioethics 481; Mark G Kuczewski "Whose Will Is It, Anyway? A Discussion of Advance Directives, Personal Identity, and Consensus In Medical Ethics" (1994) 8(1) Bioethics 27; Allen Buchanan "Advance Directives and the Personal Identity Problem" (Autumn, 1988) 17(4) Philosophy and Public Affairs 277; although the approach is open to debate: Helga Kuhse "Some Reflections on the Problem of Advance Directives, Personhood, and Personal Identity" (1999) 9(4) Kennedy Institute of Ethics Journal 347 doubted Buchanan's approach as being questionable.

[145] Nancy K Rhoden "The Limits of Legal Objectivity" (1990) 68 NCL Rev 845 at 847.

[146] Ibid., at 857.

it the right to be respected.[147] King reasoned that a person who makes a living will has exercised her right to decide; most people see their preferences, goals and values as being relevant to their future selves, because they see themselves as unified subjects of their lives.[148] A previous directive, as such should be respected and the AD to carry authority, because, to treat a patient who was previously competent as no different from a never-competent patient is hardly acceptable.[149] The 'narrative identity' that people ascribe to their lives means that their wishes should not be ignored; thereby extending the critical interests even when they are no longer able to experience them.[150]

The "stranger" argument, as the critiques of ADs contended, does not appear to be a main concern in practice and in the courts. In so far as the courts are concerned, the now incompetent person is still the same person who made the AD.[151] This approach recognises the significance of prior wishes and takes into account the interests of the now incompetent person. It is only the interests that have changed, not the person. The cases thus far illustrate that the personal identity issue is not really considered by the courts. The courts were concerned with whether the decision was still valid and applicable and, if not, the best interest of the patient. As to the "black box" argument, the courts have generally not discounted the person's AD merely because the individual is inexperienced in how their illness would affect their perception about future treatment.[152] The recognition of the right to refuse treatment does not hinge upon the reasons for deciding as such. A person is entitled to make decision even if it is a rash, ill informed decision. Requiring experience in treatment presupposes that all decisions must be informed. This is not necessarily so in medical decision-making. A contemporaneous refusal can be uninformed in that people can actually waive the right to be informed. In this sense, Dresser failed to take into account King's argument that the right to decide extends to all forms of decisions. A decision need not display reasoning. Although the question of personal identity and ADs remains a contested issue, but as described above it does not appear to be within the courts' consideration.

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[147] Nancy M P King *Making Sense of Advance Directives* (Georgetown University Press, Washington DC, 1996) at 88.

[148] Ibid.

[149] Paul T Menzel "Voluntarily Stopping Eating and Drinking: A Normative Comparison with Refusing Lifesaving Treatment and Advance Directives" (2017) 45 The Journal of Law, Medicine & Ethics 634 at 641. https://doi.org/10.1177/1073110517750602.

[150] Ibid.

[151] Derek Morgan "Odysseus and the binding directive: only a cautionary tale?" (1994) 14 Legal Stud 411 at 438.

[152] For example, the English High Court in *Re B (adult: refusal of medical treatment)* [2002] EWHC 429 (Fam) expressed that Ms B's inexperience does not preclude her from refusing further treatment. Except for one English decision, *W Healthcare NHS Trust v H and others* [2004] EWCA Civ 1324 where the court, as part of the reasoning viewed KH's inexperience as insufficient to justify the discontinuation of feeding.

2.2.2.2 ADs Are Impractical to Implement

Fagerlin and Schneider objected to ADs from this perspective, disputing the AD's utility, citing its impracticality when it comes to implementation.[153] Their claims can be broadly classified into five aspects, in no particular order. Firstly, they claimed that patients are either misinformed or uninformed and deficient in having well considered preferences. These deficiencies contributed to ADs being too unclear to be applicable. Next, patients experienced difficulty with articulating what they want, which resulted in using vague terms in the ADs. Thirdly, the danger with ADs lies in the potential for change of mind, citing the example of a pregnant woman, who had previously expressed her refusal to using anaesthesia before going into labour but had changed her mind after that. Fourthly, they criticised AD forms which are primarily unworkable, because some forms contain instructions which are either too general or too specific, could not be located, and not reviewed after a period of time. Finally, doctors are unable to interpret the ADs when it is time to execute them, which then leads to the failure to have its desired effect, thus implying it does not work.

While Fagerlin and Schneider's claims may have some validity, they are by no means irremediable to the point of disregarding ADs in total. Their claims that ADs failed can be attributed to the decision-making process in creating the ADs. The problem of a patient becoming uninformed or misinformed can be remedied, by having discussions with doctors about the future treatment prior to becoming incompetent. The patient can be supported by a doctor's explanation about any treatment, the nature and consequences of the decision or clarify any misunderstanding. As to the question of change of mind, this is a crucial distinguishing factor between contemporaneous refusal and ADs. ADs tend to be misconceived as being irrevocable, which is untrue. A person, while competent, can change his or her mind about future treatment, and to this extent, revoke their prior refusal. There is nothing to stop them from departing from the AD. In addressing the issue of uncertainty about the changes of circumstances that may occur after the making of AD, King made an excellent point that uncertainties can never be eliminated entirely, but that individuals can be encouraged to take actions to remove such uncertainties, for example, through periodical revalidation.[154]

Another challenge concerns the utility of AD forms, which, when put to the test, suffer from a lack of clarity. This situation can occur where the terms are too general to implement or where they are too specific that the circumstances become inapplicable. However, there is reason to suggest that the forms provide a clue as to the expression of preferences of the now incompetent patient. There is all the more reason to record the preferences in writing, as the *Cruzan* decision demonstrated that clear and convincing evidence is required before the decision carries highly

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[153] Angela Fagerlin and Carl E Schneider "Enough: The Failure of the Living Will," (March–April 2004) 2 Hasting Center Report 30.

[154] Nancy M P King *Making Sense of Advance Directives* (Georgetown University Press, Washington DC, 1996) at 81.

persuasive weight. This leads us to another related point about over-zealousness with forms comprising of checkboxes in some ADs. While there is nothing wrong with requiring clear and convincing evidence that the patient has refused treatment, it would defeat the purpose of AD if we begin to slavishly adhere to forms as a way of measuring the validity of ADs. Insisting that an AD is only valid if it complies with a particular set of forms or format may not necessarily indicate that a decision is arrived at genuinely. Rather, what is important is the decision-making process involved in an AD. A person who has participated in making an AD with the assistance of a doctor or healthcare professional is in a better position to understand the significance of the decision compared to a person who completed a standard AD form without the benefit of medical advice.

Despite these criticisms towards ADs, Fagerlin and Schneider conceded that ADs are not to be eliminated in their entirety and agreed that ADs can be useful for clear-cut cases, citing the example of terminally ill individuals or where death is imminent.[155] They advocated the use of an enduring power of attorney as a form of future decision-making.[156] Their critique points to a crucial understanding of ADs, that it is uncertain whether the AD represents an individual's genuine, autonomous decision, because when it is called into implementation, there is no opportunity to verify that decision.

Kutner's opponents did not appear immediately to challenge the idea at the time when it was first conceived. It was only much later from the 1980s onwards when ADs' popularity soared that concerns about their application came under scrutiny. Although the critics viewed ADs as failing to promote their autonomy, it is important to recognise that all treatments come with risks; with such risks being amplified in ADs because of the nature of the process of decision-making. What Fagerlin and Schneider failed to address is the differences between a contemporaneous treatment refusal and an AD. ADs that possess the qualities of contemporaneous refusals can be binding. While the critics, except for May, do not specifically point out this distinction, those uncertainties which they highlighted can be remedied with the supported decision-making approach which I will explore in Chap. 4.

The distinction between a contemporaneous refusal and an AD is significant because it affects the outcome of the AD. King accurately identified that an AD lacked the "same luxury of simply declaring themselves and no exchange on which to build any assessment of the decision process."[157] In order for ADs to operate, King advocated some assumptions must exist.[158] Examples of such assumptions are that the makers of ADs have forethought and considered the consequences of their choices, that they are autonomous people and not to "second-guess the authors of directives, to argue that they could not really have anticipated what their cir-

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[155] Angela Fagerlin and Carl E Schneider "Enough: The Failure of the Living Will" (March-April 2004) 2 Hasting Center Report 30 at 37.

[156] Ibid., at 39.

[157] Nancy M P King *Making Sense of Advance Directives* (Georgetown University Press, Washington DC, 1996) at 104.

[158] Ibid., at 105.

cumstances would be like and that they might have changed their minds."[159] These assumptions enable the opportunity to incorporate some measures to help achieve the validity of an AD and result in a higher likelihood of being binding.

The main objections mounted by opponents towards ADs are of two distinct types: those related to their distinctive features and those directed to their practical use. The former has the effect of objecting to the concept of ADs in its entirety, while the latter relates to its binding status. This book is premised upon the basis that an AD is a useful tool in medical decision-making as an expression of personal autonomy, and I propose ways to render it more likely to become binding, having due regard to its distinctive characteristics compared to contemporaneous refusals. As such, the second objection to ADs warrants closer scrutiny because these concerns—the process of decision-making in an AD—become increasingly significant as they are emphasised in the judicial disputes. Similarly, the adequacy of the existing understanding of autonomy as it is applied in the AD context needs to be examined to make ADs effective as expressions of autonomy.

2.3 Conclusion

The convergence of historical, social and medical factors created numerous opportunities to transform the dynamics in the doctor-patient relationship and the opportunity for ADs to develop, and become applicable in medical law, premised on the principle of autonomy. There is less absolute reliance on the doctor's expertise as a result of the cumulative events described above, which tipped the balance in favour of patient empowerment. ADs are increasingly accepted in medical decision-making at the end-of-life. It has become legally recognised as part of the healthcare services throughout the common law world, either in statute or case laws or codes like New Zealand. This trend has proceeded to the extent where ADs refusing treatment are accepted, but not necessarily binding. What remains controversial is the extent to which ADs bind healthcare professionals. This controversy can be attributed to the fact that there is no opportunity to verify the AD by the time it becomes operative. Doctors are uncertain if the ADs still represent the wishes of the patient and, significantly, whether they have been properly advised in the course of committing themselves to the decision. Without such assurance of certainty, doctors and judges become indisposed to uphold the ADs.

While there were supporters in ADs, people who opposed ADs have been quick to point out the flaws and challenges of and alternatives to ADs, instead of offering practical ways to remedy their limitations. Additionally, opponents of ADs attacked their legitimacy as a mechanism in promoting patient autonomy in healthcare decision-making. It must be remembered that Kutner proposed the AD concept in response to the unsatisfactory position in criminal law, taking into account the duty of the

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[159] Ibid.

state to protect lives. There is reason to infer that proponents of ADs would favour recognition of legally binding ADs that are to be followed in the event of incapacity.

Advance care planning that developed in parallel to ADs become the preferred alternative but while they provide a certain degree of autonomy, this sense of autonomy is false because they are not perceived as binding. Those views are taken into account in the best interest of the patient when a decision needs to be made. Advance care planning does not resolve the heart of the challenge to ADs and are only potentially useful as a starting point to create an AD. The resistance to legally binding ADs reflects a reality that while patients can contemporaneously refuse treatment, the uncertainties with implementing ADs are major drawbacks that make ADs harder to be accepted. It is thus essential that people are supported in the process of making ADs, drawing from available resources, for example family members or individuals nominated by the person. The legal responses to making ADs are considered in the next chapter.

Chapter 3
Legal Responses to the Challenges of Making Advance Directives

3.1 Introduction

The decision-making process in ADs is a key issue that is heightened when disputes about withholding and withdrawing treatment came before the courts. The courts in United Kingdom, New Zealand, Canada and Singapore dealt with a range of applications from either the hospitals or the families of patients concerning the implementation of the patient's ADs. The range of cases drawn from the four jurisdictions below illustrated the challenges with creating and applying ADs, with a focus on two key aspects—the validity and applicability of the ADs.

3.2 Case Study I: England and Wales

3.2.1 Advance Directives Under the Common Law

3.2.1.1 The Validity of the Advance Directives: Capacity, Voluntariness and Understanding

Generally under the common law, the person must be mentally competent, acting voluntarily at the time of making the AD and must have a full understanding of the nature and effect of the AD.[1] As such, lack of competence, understanding, or voluntariness invalidates ADs. For example, in the English case of *Re C*,[2] the issue in question was the patient's mental capacity in refusing amputation of the right foot.

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[1] For example, *Re T* [1992] EWCA Civ 18; *HE v A Hospital NHS Trust & AE* [2003] EWHC 1017 (Fam); *NHS Trust v T (adult patient: refusal of medical treatment)* [2004] EWHC 1279 (Fam); *Re C (refusal of medical treatment)* [1994] 1 WLR 290 (Fam).

[2] *Re C (refusal of medical treatment)* [1994] 1 WLR 290 (Fam).

H. Y. Chan, *Advance Directives: Rethinking Regulation, Autonomy & Healthcare Decision-Making*, International Library of Ethics, Law, and the New Medicine 76,
https://doi.org/10.1007/978-3-030-00976-2_3

He suffered from chronic paranoid schizophrenia, a type of mental disorder when he was first admitted into Broadmoor, although his condition had improved over the years. Mr C was in prison when he developed gangrene in his right foot. To save his life the foot needed to be amputated, but Mr C refused at the peril of death. He was informed and knew and understood the consequences of refusing the amputation.

Doctors and specialists who were either involved with his care or examined him include a consultant forensic psychiatrist who was also his resident medical officer at Broadmoor, a consultant vascular surgeon, a consultant psychiatrist at the hospital and a consultant and senior lecturer in forensic psychiatry. The doctors found him to be competent when he refused the amputation. The fact that he was suffering from schizophrenia did not mean that he lacked the capacity to refuse an amputation of his limb. Two of the medical specialists who assessed his capacity found that his refusal did not relate to his delusions. The Court accepted this finding and preferred to determine whether his mental capacity was reduced by his mental disorder.

This case revealed the court's approach towards determining a person's mental capacity in refusing treatment intended to bind the doctors in the future. It appears that rather than presuming Mr C's mental capacity, the court sought positive evidence from doctors and specialists who had assessed Mr C to arrive at the finding that his mental disorder had not impaired his mental capacity to decide. An alternative interpretation could be the case that the court applied a weak presumption of capacity where all the hospital had to do was to put Mr C's capacity at issue and it was then Mr C's burden to prove that he had the capacity at the material time. Mr C's case is an early indication that a person's mental capacity for refusing treatment for an AD is no higher than that required of a contemporaneous refusal. The requirement that a person is mentally competent is now enshrined in the English Mental Capacity Act 2005.[3]

The second example that demonstrated the importance of possessing mental capacity when making an AD was *NHS Trust v T (adult patient: refusal of medical treatment)*.[4] Ms T suffered from a mild personality disorder and perceived her blood as evil. In attempts to rid the evil off her body, she would cut herself and let the blood out, which resulted in low haemoglobin requiring blood transfusions. She had reacted negatively whenever blood was transfused although the healthcare providers had successfully persuaded her to accept transfusion on previous occasions.[5]

The court found that she had a misperception about her blood being evil, as opposed to irrationality.[6] Ms T's mental disorder related directly to her refusal and hence her AD refusing a blood transfusion was held to be invalid. Charles J accepted the evidence of T's psychiatrist Dr C who formed the opinion that Ms T had always been delusional and disordered to the extent of deeply impairing her mental capacity to decide.[7] Referring to *Re T* and *Re C,* Charles J inferred from Ms T's history of

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[3] Mental Capacity Act 2005 (UK), ss 24-26.

[4] *NHS Trust v T (adult patient: refusal of medical treatment)* [2004] EWHC 1279 (Fam).

[5] Ibid, at [6].

[6] Ibid, at [61].

[7] Ibid.

illness that she would have been incapable of making any such refusals in the past and unlikely to possess the required mental capacity in the future. Although her AD explicitly set out the reasons for her refusal, demonstrating that she understood the nature and effect of refusing a blood transfer, and further accompanied by a letter from her doctor confirming her understanding of the effect of the AD, it was insufficient to persuade the Court that she had the required mental capacity to refuse a blood transfusion. Instead, her refusal was taken to be a manifestation of the mental disorder and thus not regarded as valid. In contrast to Mr C, his refusal co-existed with his mental disorder but was not considered to be a symptom of it and thus did not affect his ability to consent or refuse treatment.

Ms T's decision illustrates how pre-existing mental disorders could affect her mental capacity at the time she made the AD. Consequently she would not be presumed to have been mentally competent when she expressed her refusal to accept blood transfusion. The retrospective assessment of capacity on the face of it defeats the purpose of the presumption in the first place. The presumption of capacity demands that a person is presumed to be competent until proven to the contrary; yet in this case the approach appears to suggest that a mentally disordered person is mentally incompetent until evidence is furnished to demonstrate that the person is competent at the time the AD is made. Although the four psychiatrists who examined her were divided about whether she was mentally competent when she made her AD, it nonetheless illuminated the significance of a doctor's role in providing proof of mental capacity when making an AD. In both cases the courts turned to the doctors' assessment of the patient's mental capacity in assessing the validity of the AD.

A case that dealt with not only the person's mental capacity but the voluntariness and understanding of the information pertaining to the refusal in making an advance refusal for blood transfusion was *Re T*.[8] This decision illustrated a contemporaneous refusal that became an AD because she had purportedly refused blood transfusion on the basis of her residual belief as a Jehovah's Witness prior to becoming incapacitated. Miss T's parents had separated when she was a child, and she had lived with her mother who was a devout Jehovah's Witness.[9] Her mother was expressly prohibited from converting Miss T into a Jehovah's Witness pursuant to a custody order.[10]

Miss T became pregnant when she was 17 or 18 years old. She was hospitalised following a traffic accident.[11] She subsequently developed pneumonia and was prescribed antibiotics and narcotic drug.[12] Her condition did not improve and she continued to receive the administration of the narcotic drug. It was at the stage where she was administered with the drug that she expressed the "possibility of a blood transfusion" for the first time.[13] When she went into labour she had then refused

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[8] *Re T* [1992] EWCA Civ 18.

[9] *Re T* [1992] EWCA Civ 18 at [7].

[10] Ibid, at [7].

[11] Ibid, at [9].

[12] Ibid.

[13] Ibid, at [13].

blood transfusion whereupon she signed a refusal of consent form.[14] After delivering a stillborn baby her condition deteriorated to the point of being ventilated and sedated.[15] Her father and her boyfriend then applied to the court seeking a transfusion, in view of the hospital's inability to act on the transfusion because of the existence of her residual belief, which could not be established with certainty.

The trial court at the first hearing found that Miss T was mentally incapacitated to refuse blood transfusion after hearing evidence from Dr F whom T had expressed her refusal and who had the opportunity to observe and speak to her.[16] However, in the second court hearing, the trial court found that T was mentally competent, following a change in Dr F's report about T's mental capacity.[17]

The Court of Appeal affirmed the trial court's judgment. The Court referred to the evidence of the doctor who treated Miss T. The doctor opined that she was influenced by the sedative, mentally incompetent and had not assessed the gravity of the situation.[18] The condition continued even when she signed the refusal form. It shows that once a patient's competence or understanding has been put in issue, as Miss T's was because of her pain and the medication she was on, the Court will require evidence of the patient's competence at the time of refusing treatment, furnished by doctors.

Essentially, the Court of Appeal had indicated that capacity should be commensurate with the gravity of the decision,[19] an aspect which would be true of a contemporaneous refusal.[20] So if it is a refusal that leads to death, then the person has to possess and demonstrate a mental capacity equivalent to making that decision or even presumably, a higher degree of mental capacity. No such evidence was presented in *Re T* and hence the Court was not satisfied that the AD was valid. Additionally, the Court of Appeal addressed the conflict of principles between the sanctity of life and a person's autonomy to refuse treatment.[21] Lord Donaldson emphasised:[22]

> Society's interest is in upholding the concept that all human life is sacred and that it should be preserved if at all possible. 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 the preservation of life for if the individual is to override the public interest, he must do so in clear terms.

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[14] Ibid, at [15].

[15] Ibid, at [16].

[16] Ibid, at [17].

[17] Ibid, at [19].

[18] Ibid, at [17].

[19] Ibid, at [28].

[20] See for example *St George's Healthcare NHS Trust v S* [1999] Fam 26 where the pregnant patient Ms S's mental capacity was challenged when she refused contemporaneously to give birth via Caesarean section, a refusal which risked her life and the life of her unborn child.

[21] *Re T* [1992] EWCA Civ 18 at [26].

[22] Ibid.

This signifies that autonomy is not paramount and it is rebuttable when the refusal conflicts with the sanctity of life. Lord Donaldson MR further explained that a person's mental capacity became relevant in tipping the balance when the nature of a choice is questionable.[23] This appeared to suggest that although a person is presumably allowed to refuse treatment for whatever reason, this does not seem to be the case when the doctor is unable to verify the reasons for such refusal. In Miss T's case, the Court of Appeal may have been inclined towards a presumption in favour of saving life, which was not rebutted because T had become incompetent. If the court in Mr C's case had applied the same presumption, it would have been rebutted by Mr C's oral evidence and the court's opportunity to observe and speak to him.

Additionally, another issue concerning *Re T* was her voluntariness in refusing blood transfusion. The Court of Appeal affirmed the trial court's finding and concluded that there was ample evidence to suggest that Miss T was not acting voluntarily when she refused the blood transfusion. Her physical and mental state was weakened as a result of pain and the sedative medication she was receiving. Furthermore, she was subject to undue influence from her mother at her bedside when she was at her vulnerable state.[24] Hence, if the patient's voluntariness has been put in issue, the Court will require clear evidence that the decision was the expression of the patient's free will.

However the Court did point out that the "extent and effect of the intervention of the mother"[25] was a significant factor in ascertaining the genuineness of her decision. It was very likely that her mother's influence had overpowered her voluntariness in refusing the transfusion because she had expressed such intentions only after spending some time with her mother while being transported. The Church's press statement confirmed that Miss T was never a Jehovah's Witness.[26] It had been her mother's intention all along that she kept to the beliefs of a Jehovah's Witness although she was never one. It can only be assumed that she had not intended to be a Jehovah's Witness despite being brought up by her mother. Further, when she revived the father-daughter relationship, she had indicated to her father that she was not a Jehovah's Witness.[27]

Finally, the issue of Miss T being misinformed arose in the same case. The trial court found that she had not refused it at all cost, because she had been misinformed about other available options and the risks of refusing blood.[28] She had signed the refusal form where the content of the refusal was not explained to her, nor was she alerted to the statement in the form that transfusion may be given to save her life. Taken in totality, the court found that there was "no evidence that she did wish to persist in a refusal of a blood transfusion even if it was at risk to her life".[29]

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[23] Ibid, at [30].

[24] Ibid, at [22, 23].

[25] Ibid, at [45].

[26] Ibid, at [7].

[27] Ibid, at [8].

[28] Ibid, at [15, 19].

[29] Ibid, at [19].

Re AK was a completely different case from Miss T.[30] Mr AK suffered from a rapidly progressive degenerative motor neuron disease and requested to stop artificial ventilation, nutrition and hydration (ANH) once he became unable to communicate.[31] He had been suffering from the disease for 2½ years and would slowly degenerate, losing the use of his muscles, until he could no longer breathe, and would die as a result. He suffered a respiratory arrest for which he was ventilated prior to a diagnosis of motor neuron disease. Unlike other degenerative disease, he became locked in, resulting in his inability to move his body other than his eyes. Consequently, he could be experiencing problems which others would not know. It was through his eyelids movements that he communicated with his doctors and carers. However, as the illness progressed, he would soon lose this movement.

He was fully aware of his emotions and surroundings, wanted to be kept informed about his disease; knew about the irreversible nature, progress and consequences of the disease, and understood that he would eventually die. When it was clear to the doctors that AK would soon lose the ability to communicate, the care coordinator informed AK about this. Three days later AK decided that two weeks after he lost the ability to communicate, ANH should be discontinued, and this was duly recorded using the "E-transboard." After the consultant explained to AK about the consequences of ceasing ANH, he knew that once the ventilator was switched off, he would die from the inability to breathe and his doctor would administer sedative drugs so that he would not be aware of what was then happening.[32] AK understood the whole process and confirmed his decision via painstaking procedures using his limited eye movements. After recording his wishes in the AD, the care coordinator confirmed with AK the next day by asking him the same questions in the presence of his mother and another carer.[33] A few days later his doctor arranged for an independent consultant anaesthetist and a palliative care specialist to see AK and they asked him the same questions.[34] Again they obtained the same answers.

The doctors having satisfied themselves of AK's clear wishes, the Healthcare Trust wanted to know if it was lawful to withdraw ventilation for AK when the specified time came. The Trust applied to the Court for a declaration.[35] The Court then arranged for a solicitor to represent AK's interest. The solicitor visited AK and communicated with him using the same method of communication. He explained to AK about the application to the Court to effectuate his wishes, which AK understood.[36]

The Court was satisfied that all three requirements for validity were present. There was medical evidence that he was competent when he made the decision that treatment should be withdrawn when he lost the ability to communicate. While his family was supportive of his decision, there was nothing to suggest AK was

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[30] *Re AK (Adult Patient)(Medical Treatment: Consent)* [2001] 1 FLR 129; [2000] 58 BMLR 151.

[31] Ibid.

[32] Ibid, at 154.

[33] Ibid.

[34] Ibid, at 155.

[35] Ibid.

[36] Ibid.

unduly influenced by his family. From a legal point of view, whether or not his family supported his decision was irrelevant.[37] Although AK had been suffering from the disease for some time and knew what the future held for him, the Court did caution that the decision needed to be reviewed to ensure that it still represented AK's wishes.[38] Unlike Miss T who was under the influence of sedatives that gave rise to doubts about her mental capacity, AK was not under the influence of drugs or pressures from anyone when he decided to stop the ANH.

Some preliminary conclusions can be drawn here about the validity of the ADs under the common law. When a court is called upon to determine the validity of an AD, it will look into the mental capacity of the person at the time of making the AD, the voluntariness and the understanding of the refusal. Proof of capacity assures the court that the patient knows what they are refusing. In ascertaining these factors the court will often turn to evidence from doctors who had the opportunity to assess the person. In most instances, the doctor does not have a chance to do so, maybe because of an emergency situation, such as an urgent blood transfusion or life threatening situation. Cases similar to AK and Mr C are rare where the requirements for valid ADs were satisfactorily met.

The handful of cases examined so far did not seem to point conclusively to whether the courts applied a different standard for mental capacity to ADs than to contemporaneous refusals. But there is reason to suggest that in a contemporaneous refusal, while the courts may be inclined to apply a de facto presumption of saving life, such presumption can be readily rebutted by evidence of capacity, such as in the cases of Mr C or Mr AK-type. The opportunity to speak to, or observe the patient will be impossible in ADs such as in the case of Miss T. Thus, it may be that the best approach is to minimise the incidence of such cases by involving a medical or psychology/psychiatry professional at the time of writing the AD. Taking this step may not necessarily *guarantee* that the court will uphold the validity of the AD, and there is always the possibility of such ADs being open to the challenge of subsequent changes. However, where doctors supply proof of mental capacity seems to provide the best prospect of the AD being upheld.

3.2.1.2 The Applicability of the Advance Directives: Clarity, Scope and Subsequent Changes

While an AD may be valid, in that the person was mentally competent, acting freely and with understanding, the AD may be ambiguous, too vague, or inapplicable to the circumstances that have arisen. In any of those situations, the English courts will not uphold the AD. *W NHS Trust v H and others*[39] illustrated concerns regarding

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[37] A point about the family's or relatives' role was highlighted in *Re T* where the Court of Appeal pointed out that families or relatives have no legal right to consent to or refuse treatment on behalf of the patient: *Re T* [1992] EWCA Civ 18 at [6].

[38] Ibid, at 156.

[39] *W Healthcare NHS Trust v H and others* [2004] EWCA Civ 1324.

the weight to be attached to prior expression of wishes, taking into account the context in which it was made. Ms KH suffered from multiple sclerosis and was fully dependent on the carers at the nursing home. Her doctors and family agreed that she was incapable of consenting to medical treatment.[40] Her plight came before the court due to a disagreement between her family and the doctors regarding the reinsertion of a feeding tube which had fallen off.

The question turns to KH's wishes which were purportedly made when she was still mentally competent. Several pieces of evidence furnished by family members and close friends revealed KH's wishes not to be kept alive by machines and not to be a burden to her daughters if she could not look after herself, suggesting a strong inference that KH would not want to exist in her current state, and consequently she would refuse consent to reinsert the feeding tube. The Court granted the declaration on the basis that there was no clearly expressed AD refusing treatment when she was competent. There were also doubts about the scope of her refusal and that her refusal might be subject to the challenge of subsequent changes. Her daughter and her brother appealed the decision but the Court of Appeal upheld the High Court's decision. The Court found that KH's wishes were not specific to withdrawal of feeding and they were made years ago without the benefit of medical expertise to advise her about the nature and consequences of her refusal.[41] Although the Court plainly felt torn by KH's plight,[42] the Court had to consider the principles of best interest and sanctity of life.

This decision demonstrates that unless there is a clear and applicable declaration of refusal, then the AD would not bind the doctors.[43] This stood in contrast to AK who knew the procedure when the ventilator was removed and how death would occur. In addition, his doctor had explained to AK about future discovery and the limitations of treatment, which AK had understood[44] and had assumed the risk, considering the chance of subsequent changes occurring to be remote. KH's refusal was based on a hypothetical situation without full contemplation of her situation, unlike AK whose medical prognosis was certain.

Assuming that KH had made a valid AD, its application in the circumstances that have arisen was doubted by the Court because her refusal was vague as to its meaning. For example, it was unclear as to whether what level of "burden" would be acceptable to her or whether she would only refuse treatment if she became permanently incompetent. In the cases examined above, the court was clear about what the patients were refusing—blood transfusion, amputation of leg and ceasing ventilation.

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[40] Ibid, at 836.

[41] Ibid, at 839.

[42] Ibid.

[43] Ibid, at 838.

[44] Ibid, at 155.

An example of a subsequent change of circumstances and change of mind that affected the AD is the case of AE.[45] AE was the 24-year-old daughter of Mr HE. AE was initially brought up as a Muslim. However after her parents separated, she became a Jehovah's Witness, adopting her mother's faith.[46] She had an AD refusing blood transfusion, although the circumstances under which the AD was made were questionable. AE needed surgery due to suffering from a congenital heart disease.[47] Her doctor noted her religious belief in her medical records and planned her surgery without the need for a blood transfusion.[48] Nevertheless, before the intended surgery took place, she became gravely ill necessitating blood transfusion, failing which she would die.[49] AE lapsed into unconsciousness before any confirmation could be obtained. The doctors were prevented from transfusing her because of her AD.[50]

AE's mother had informed the doctor upon admission that AE's religious belief meant that she should not be transfused.[51] In the meantime, she was sedated and the doctors were able to stabilise her for a short period of time, after which her condition worsened, whereupon blood transfusion became inevitable. Her father, HE opposed the claims by producing evidence demonstrating that AE had changed her mind about being a Jehovah's Witness, thereby revoking her AD refusing blood transfusion. The Court preferred HE's evidence and rejected the AD, on the basis that AE's personal circumstances had changed since her AD was made and that it no longer applied.[52]

Munby J discussed the burden and standard of proof on the continuing validity and applicability of an AD. The Judge held that the burden of proof is on those who seek to rebut the presumption claiming that the person lacked the mental capacity at the time of making the AD.[53] The test for establishing the continued validity and applicability of AE's AD was convincing and inherently reliable evidence.[54] Munby J did not appear to outline the ingredients of clear and convincing evidence, but mentioned that examples of evidence of subsequent changes could include spoken words or conduct contrary to the ADs that threw doubts on it.[55] Additionally, although Munby J emphasised the importance of "close, rigorous and anxious scrutiny" of the AD to determine whether it is still valid and applicable,[56] it is unclear what it means and how to ascertain that level of scrutiny.

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[45] *HE v A Hospital NHS Trust & AE (by her litigation friend the Official Solicitor)* [2003] EWHC 1017 (Fam).

[46] Ibid, at [2].

[47] Ibid, at [3].

[48] Ibid, at [5].

[49] Ibid, at [6].

[50] Ibid, at [12].

[51] Ibid, at [7].

[52] Ibid, at [26] to [32].

[53] Ibid, at [20].

[54] Ibid, at [23], [24].

[55] Ibid, at [43].

[56] Ibid, at [25].

In this case AE's father was able to articulate the changes that had occurred to AE. Although it cannot be said with absolute certainty that AE did change her mind, the evidence produced by her father had convinced the Court to a persuasive extent that she had taken steps indicating the changes. That possibly tipped the balance towards revoking her AD. On the other hand, if her father was unable to produce such evidence, the likely approach in resolving doubts about the continued validity and applicability of the AD is by erring on the side of preserving life and the doctor would treat AE in her best interest.[57]

An ancillary issue that arose was the presumption in relation to the continuing validity and applicability of AE's AD. Munby J held that there was no presumption of effectiveness of ADs, where the AD was presumed to be valid until proven otherwise. The presumption of effectiveness of an AD can be rebutted with the presumption in favour of preserving life. The Judge referred to Lord Donaldson's dictum in *Re T* where in cases of conflicts between the patient's right to autonomy and society's interest in preserving life, the doubt should be resolved in favour of preserving life. If a person failed to establish that an AD continued to be effective, then the presumption fell in favour of life. On the other hand, if there is no such presumption to start with, this would leave ADs too vulnerable to being undermined by family members, such as AE's father in this case who can raise these doubts. The burden then shifted to the mother to assert the continued validity and applicability of the AD because the father's evidence had raised doubts on AE's AD. Whether the doubt is real or speculative would depend on the facts and circumstances.[58]

3.2.1.3 Conclusion

We can see from the above sample of common law cases that they can be broadly classified into three types of cases; a classification derived from the cases of *Re C*, *Re AK* and *Re T* respectively. They are the "C" type case, where the court has the chance to question the patient; the "AK" type case, where the court has no such chance, but the patient's capacity was confirmed by the medical staff treating him; and the "T" type case, where no such opportunity existed for anyone to confirm capacity. Therefore, T-type cases and AK-type cases are opposites. However, a T-type case can be remedied by the opportunity for the patient to speak to the court or the doctor so that it has the qualities of an AK-type case or at the very least a C-type case.

The common law established that an AD made by a mentally competent person who had acted voluntarily with an understanding of the nature and consequences of refusal would be upheld. Although the presumption of capacity was said to apply, in the cases considered above, the courts would always look for proof of mental capacity in cases of refusing life saving treatment. It is more likely that requiring evidence of mental capacity applies in contemporaneous refusals and ADs. The requirements for

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[57] Ibid, at [43].

[58] Ibid, at [44].

information and understanding the nature and consequences of refusals in ADs were not different from contemporaneous refusals. Some of the common law rules that developed from the case law considered above were clarified in the Mental Capacity Act 2005 that came into force in 2007. Additional formalities were introduced for specific ADs.

3.2.2 Advance Directives Under the Mental Capacity Act ("MCA") 2005

3.2.2.1 Introduction

A Living Will Report produced in 1988 considered possible approaches in addressing concerns raised by the uncertainties of the legal position concerning withdrawing and withholding of treatment in the face of ongoing medical progress in the UK.[59] The uncertainty was also prompted by an absence of statutes governing ADs. Although the Report did not recommend any particular course of action, it provided a range of options to consider in the future. The Report considered the role of ADs and concluded that any prior wishes of a previously competent person would be merely "directory" and not binding on the doctors.[60] The legal position was then clarified with the enactment of the MCA.

ADs are legally recognised in the MCA. The Act came about following extensive consultations and publications of the Law Commission Report No. 231 on Mental Incapacity in February 1995, and the *Making Decisions* consultation paper in October 1999. The *Making Decisions* consultation paper examined the feasibility of legislating ADs in view of their acceptance in the common law.[61] Following these background reports, a draft Mental Incapacity Bill was published and examined by a Joint Committee. The government's response to the Joint Committee's report on the Mental Incapacity Bill was presented before the Parliament.[62] The Bill was introduced in an attempt to:[63]

> reform the law in order to improve and clarify the decision making process for those aged sixteen and over who are unable to make decisions for themselves as well offering the people with capacity the choice to decide how they are cared for in the future by introducing new ways to plan ahead for a time when they might lose capacity.

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[59] Report under the auspices of Age Concern Institute of Gerontology and Centre of Medical Law and Ethics, King's College, London "The Living Will: Consent to treatment at the end of life" (Age Concern England, Great Britain, 1988).

[60] Ibid, at 48.

[61] *Who decides? Making decisions on behalf of mentally incapacitated adults: A consultation paper* issued by the Lord Chancellor's Department Presented to Parliament by the Lord High Chancellor by Command of Her Majesty December 1997 (Cm 3803).

[62] Explanatory Note to the Mental Capacity Act.

[63] (24 February 2004) 658 GBPD HL c16WS.

The MCA, together with a companion Code of Practice clarified the common law principles of presumption of capacity, rights of bodily integrity and of autonomy relating to persons who are incapacitated by accident, disease or some other events whether temporary or long term, including the use of ADs and the roles of healthcare professionals in ADs.[64] The common law cases provided the impetus for Parliament to consider legislating ADs as a way to clarify its legal status.[65] The statute however has been received with some caution.[66] The Select Committee on Medical Ethics had previously concluded that legislating ADs would be redundant as doctors and courts are increasingly showing a tendency to comply with the ADs.[67]

The MCA describes an AD refusing treatment as an advance decision.[68] An advance decision is a decision made by a person of 18 years or older and who has the mental capacity about withholding or withdrawing specific treatments proposed to be carried out or continued when the person becomes mentally incapacitated at a future time.[69] The MCA distinguished legally binding ADs from advance statements.[70] An advance statement is not legally binding, but it serves as an informal evidentiary function of stating the values and preferences of the person. This approach arose as a compromise between acknowledging the need to respect the right to refuse treatment and clarifying the legal position of doctors who faced treatment refusals involving ADs. The Joint Committee on ADs recommended that ADs be permitted despite recognising the moral objections to mechanisms that can end life. Section 58 in its current form reflects this compromise in which the MCA does not permit euthanasia. This compromise also means that if ADs do not have a binding status, it may be more liable to be ignored, contravened or disregarded, and the decision-making process then rests upon a best interest approach, rather than autonomy.

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[64] For related commentaries to the Mental Capacity Act, see Paul Bowen *Blackstone's Guide to the Mental Health Act 2007* (OUP, 2007) at 144; Penny Letts (General Editor) *Assessment of Mental Capacity: A Practical Guide for Doctors and Lawyers* (3rd ed, BMA and the Law Society, 2010).

[65] MCA Explanatory Note at [84], [85], [86], [87], [88], [89], [91].

[66] See for example Anne Wilkinson "Living wills revived?" (1997) 147(6820) New Law Journal 1823, commenting on the UK Law Commission's decision against prescribing any formalities for advance refusals for fear of invalidating an otherwise valid advance refusal. The author is of the view that formalities would actually encourage clarity in drafting advance directive; also see S Walton "Correspondence in response to Hegde R, Bell D, Cole P 'The Jehovah's Witness and dementia: who or what defines 'best interests'? (2006) 61 Anaesthesia 802" (2007) 62 Anaesthesia 412–423. The author cautioned against viewing the Mental Capacity Act and advance directive as simple solutions to a complex problem.

[67] Report on Select Committee on Medical Ethics, vol. 1 Report, London, HMSO, HL Paper 21-1, Session 1993–1994 at 54.

[68] Mental Capacity Act 2005 (UK), s 24.

[69] The Law Commission noted that under 18-year-olds were excluded from making ADs pursuant to the "inherent jurisdiction of the court and a person exercising parental responsibility can overrule this choice"—see *Who decides? Making decisions on behalf of mentally incapacitated adults: A consultation paper* issued by the Lord Chancellor's Department Presented to Parliament by the Lord High Chancellor by Command of Her Majesty December 1997 (Cm 3803) at [4.2.1].

[70] Section 25(5) MCA.

The MCA has attracted considerable discussion by legal scholars and clinicians.[71] Doctors were interested in the effect of the MCA upon their clinical practice and their legal status[72] while legal research critically examined the extent to which decision-making provisions in the MCA promoted patient autonomy.[73] The blend of interests in the MCA is valuable in informing the research on the practical implementation of the provisions regarding ADs. The research highlighted the competing interests between autonomy and sanctity of life in treatment decisions involving ADs.[74] Carolyn Johnston accurately observed that "an attitudinal shift would perhaps be most effective" referring to the temptation to "second guess the authors of advance decisions – did they mean it, have they changed their minds, did they have capacity at the time?"[75] Additionally, Johnston correctly highlighted the benefits of having

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[71] See for example Ash Samanta and Jo Samanta "Advance directives, best interests and clinical judgement: shifting sands at the end of life" (2006) 6 Clin Med 274; Ruth Horn "'I don't need my patients' opinion to withdraw treatment': patient preferences at the end-of-life and physician attitudes towards advance directives in England and France" (2014) 17 Med Health Care and Philos 425; Darren Shickle "The Mental Capacity Act 2005" (2006) 6 Clin Med 169; Timothy R J Nicholson and others "Assessing mental capacity: the Mental Capacity Act" (2008) 336 BMJ 322; Geraldine Boyle "The Mental Capacity Act 2005: promoting the citizenship of people with dementia?" (2008) 16 (5) Health and Social Care in the Community 529; Jill Manthorpe, Kritika Samsi and Joan Rapaport "Capacity Is Key': Investigating New Legal Provisions in England and Wales for Adult Safeguarding" (2013) 25(4) Journal of Elder Abuse & Neglect 355; Rowena Jones "Review of the Mental Capacity Act 2005" (2005) 29 Psychiatric Bulletin 423; J Foster and M Turner "Implications of the Mental Capacity Act 2005 on Advance Care Planning at the End of Life" (2007) 22 Nursing Standard 35.

[72] See for example Rebekah Schiff and others "Living wills and the Mental Capacity Act: a postal questionnaire survey of UK geriatricians" (2006) 35 Age and Ageing 116; Andrew Alonzi and Mike Pringle "Mental Capacity Act 2005: Should guide doctors to help protect vulnerable people" (2007) 335 BMJ 898; Jill Manthorpe, Joan Rapaport and Nicky Stanley "Expertise and Experience: People with Experiences of Using Services and Carers' Views of the Mental Capacity Act 2005" (2009) 39 British Journal of Social Work 884; Jill Manthorpe and others "'Early days': Knowledge and use of the Mental Capacity Act 2005 by Care Home Managers and Staff" (2011) 10(3) Dementia 283; Claud Regnard and Stephen Louw "Embedding the Mental Capacity Act into Clinical Practice in England and Wales" (2011) 40 Age and Ageing 416; Nick Nicholas and Sotiris Nicholas "Understanding the Mental Capacity Act 2005: A Guide for Clinicians" (2010) 12 The Obstetrician & Gynaecologist 29; S M White and T J Baldwin "The Mental Capacity Act 2005—Implications for Anaesthesia and Critical Care" (2006) 61 Anaesthesia 381; C Schofield "Mental Capacity Act 2005—What Do Doctors Know?" (2008) 48 Med Sci Law 113.

[73] Carolyn Johnston "Advance decision making—rhetoric or reality?" (2014) 34 Legal Studies 497; Carolyn Johnston and Jane Liddle "The Mental Capacity Act 2005: A New Framework for Healthcare Decision Making" (2007) 33 J Med Ethics 94; Carolyn Johnston "Does the Statutory Regulation of Advance Decision-Making Provide Adequate Respect for Patient Autonomy?" (2005) 26 Liverpool Law Review 189; Peter Herissone-Kelly "Capacity and Consent in England and Wales: The Mental Capacity Act under Scrutiny" (2010) 19 Cambridge Quarterly of Healthcare Ethics 344; Carolyn Johnston "The Mental Capacity Act 2005 and Advance Decisions" (2007) 2 Clinical Ethics 80.

[74] Carolyn Johnston "The Mental Capacity Act 2005 and Advance Decisions" (2007) 2 Clinical Ethics 80 at 82, 84.

[75] Carolyn Johnston "Advance decision making—rhetoric or reality?" (2014) 34 Legal Studies 497 at 514.

a doctor's expertise and support in making ADs that would be binding under the MCA:[76]

> There are advantages in involving healthcare/legal professionals in the process of making ADRT, although this may not be a realistic option for those who want to take control of future healthcare decisions when they are not currently unwell nor have any anticipation of a particular illness. Those who have the onerous tasks of considering whether an ADRT meets the legal requirements and therefore should be implemented may be reassured by the knowledge that professionals were involved in the drafting process. Even so, the complexity of drafting an advance decision that is both valid and applicable may provide a challenge for both legal and healthcare professionals. Doctors may receive education/training on advance decision making at some time in their studies.

In addition to scholarly discussion on the MCA provisions, since the MCA came into force, several decisions have come before the court concerning the validity of ADs. *A Local Authority v E* concerned an anorexic patient who made an AD refusing food,[77] *Re D* was about withholding life sustaining treatment[78] and *XB* dealt with withdrawal of ventilation.[79] Cases decided after the introduction of the MCA provide a view into the approach taken in determining the validity and applicability of an AD.

3.2.2.2 The Validity of the Advance Directives: Capacity, Voluntariness and Understanding

One of the principles underpinning the MCA is the rebuttable presumption of mental capacity.[80] An adult of 18 years and possessing the mental capacity to decide can make ADs refusing treatment at a future time.[81] In respect of a person's mental capacity then, if a person at that time of making the AD is unable to decide for himself because his brain or mind is temporarily or permanently[82] impaired or disturbed, he is said to lack the capacity to decide.[83] This determination is decided on a balance of probabilities.[84] A person's age or appearance or aspects of his behaviour are not determinative of his incapacity.[85] These provide a general guide to the prerequisites

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[76] Carolyn Johnston "Advance decision making—rhetoric or reality?" (2014) 34 Legal Studies 497 at 508, 510. An empirical study demonstrated the need for further improvement and training in terms of knowledge about assessing capacity under the MCA among doctors. See C Schofield "Mental Capacity Act 2005—What Do Doctors Know?" (2008) 48 Med Sci Law 113.

[77] *A Local Authority v E (by her Litigation Friend the Official Solicitor), A Health Authority & E's Parents* [2012] EWHC 1639 (COP).

[78] *Re D* [2012] EWHC 885 (COP).

[79] *The X Primary Care Trust v XB and Anor* [2012] EWHC 1390 (Fam).

[80] MCA 2005 (UK), s 1(2).

[81] Ibid, s 24(1).

[82] Ibid, s 2(2).

[83] Ibid, s 2(1).

[84] Ibid, s 2(4); Mental Capacity Code of Practice at [4.10].

[85] Ibid, s 2(3)(a)(b).

of mental capacity. The test for incapacity is captured in s 3 of the MCA whereby a person is incapable of deciding if the person is unable to understand, retain, use or weigh the information relevant to the decision, or to communicate the decision.[86]

The first three requirements restate the requirements in *Re C*[87] under the common law, while the element to communicate the decision is an addition. Hence, if a person waves his fingers or nods his head in response to the treatment question then that would satisfy the communication element, subject to the other three requirements being met.[88] Under the MCA, "a person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success".[89] There is nothing in the MCA to suggest that the presumption of capacity and the requirements about capacity should not apply to ADs. The MCA is a marked departure from the approach adopted by the courts prior to the adoption of the MCA, where the courts always require proof of capacity.

A Local Authority v E[90] considered the provisions of ss 24-26 of the MCA 2005 on advance decisions. E was a 32-year-old woman who had, for the past 18 years, suffered from alcohol dependence, severe anorexia nervosa and personality disorder due to childhood sexual abuse and failed relationships in her adult years. She had a long history of being placed in various specialist eating disorder units and alcohol treatment units, none of which successfully treated her.[91] She had thought about making ADs in attempts to prevent the others from force feeding her.[92] She made two ADs refusing resuscitation or life prolonging medical treatment on separate occasions.[93] It occurred that she was committed under the Mental Health Act 1983 on the same day she signed the second AD. Her refusal to eat would lead to her imminent death. This prompted the hospital and the local authority to bring an application to the court declaring that it would be lawful for the hospital to force feed her.[94] E was already incompetent by the time the application was brought before the Court, having "embarked down the palliative care pathway".[95]

The Court found that E lacked the capacity to decide and on the basis of her best interest, granted the declaration sought by the hospital.[96] The main concern was E's mental capacity at the time she made the AD concerning the validity of the

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[86] Ibid, s 3(1)(a)(b)(c)(d).

[87] *Re C* [1994] 1 WLR 290 (Fam).

[88] For example, in *Re AK,* AK conveyed his intentions through eye movements and communication boards.

[89] MCA 2005 (UK), s 1(3). The MCA Explanatory Note at [20] provides an example: "making sure that the person is in an environment in which he is comfortable or involving an expert in helping him express his views.".

[90] *A Local Authority v E (by her Litigation Friend of the Official Solicitor), A Health Authority and E's Parents,* above.

[91] Ibid, at [17].

[92] Ibid, at [19].

[93] Ibid, at [20].

[94] Ibid, at [1].

[95] Ibid, at [40].

[96] Ibid, at [3].

AD. The Court suggested that E lacked the capacity to make the first AD in July because she had tried to make a second AD in October. The second AD, however, was witnessed by her mother and a mental health professional, both of whom were under the impression that she possessed the mental capacity to decide at the time it was signed.[97] Three issues came to light with the Court's approach in this case. The first deals with how the Court approached the question of capacity in respect of refusing food in an AD; the second examines the nature of the refusal while the third relates to the relationship between a person being subject under the Mental Health Act and the MCA.

In respect of capacity, the Court approached the case by asking firstly "whether the person has capacity" at the time of the hearing.[98] Jackson J framed the issue of E's treatment on the basis of her current and past mental capacity in deciding whether her AD is valid.[99] A total of 6 consultants in various relevant specialties had either cared for or examined her during her hospitalisation and illness. The Court referred to the rebuttable presumption of mental capacity and concluded that she lacked the mental capacity at the time of the hearing on three grounds: E was impaired in her mind manifested by her anorexia;[100] Her refusal was associated to her fear of food manifesting from her personality disorder,[101] much like Ms T who refused blood transfusion because of her belief that her blood was evil. Finally, she was strongly sedated resulting in a severely frail physical state.[102] The combination of pre-existing conditions which stemmed from a long history of weight battle and current state of reduced mental alertness was sufficient evidence to tilt the balance in favour of mental incapacity.

Further, the Court did not think that E was mentally competent when she made the AD because there was no evidence that she was mentally competent at that time due to an absence of a formal mental capacity assessment.[103] However the Court did not think that an assessment would have produced a different outcome.[104] This illustrated that the Court used the same criteria to deem E incompetent at the time of the hearing to deem her presumptively incompetent at the time the AD was made. At the very least, even if the presumption of capacity were to apply, E's evidence would have been rebutted.

E's case may have shown how the court approached ADs made by patients who are anorexic, but it also showed that the court wanted evidence of capacity at the time E made the AD. E's case furthermore suggested that nothing short of a full mental capacity assessment conducted by qualified specialist or psychiatrist can provide clear evidence that a person (like E) was mentally competent when the

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[97] Ibid, at [64], [65].

[98] Ibid, at [9].

[99] Ibid, at [46].

[100] Ibid, at [47], [48].

[101] Ibid, at [49].

[102] Ibid, at [50].

[103] Ibid, at [64], [65].

[104] Ibid.

person made the AD. The Court moreover indicated the necessity of possessing such mental capacity as was commensurate with the gravity of the decision, due to the fact of such a decision being “momentous” in nature, which is similar to the Court’s approach to mental capacity in *Re T*[105] examined earlier.

There is also a basis to suggest that the main reason the Court found E mentally incapacitated to refuse food was because of E’s fear of food and weight gain. On this point, the Mental Capacity Code of Practice used E’s example to illustrate an anorexic’s “compulsion not to eat might be too strong for them to ignore” resulting in them failing to “understand information about the consequences of not eating.”[106] The Court appeared to rely extensively on the court-appointed expert, Dr Glover’s evidence on E’s mental capacity, who was a consultant in eating disorder psychiatry and an expert in very severe eating disorders.[107] He opined that “anyone with severe anorexia would lack capacity to make such a decision.”[108]

It is worth reflecting upon the close association that the Court makes between a person’s mental capacity and the nature of the refusal. This approach is similar to the courts in T-type cases (for example in *NHS Trust v T*) where the court found Ms T to be incompetent to refuse blood transfusion because her mental disorder (she had habitually caused herself to bleed because of her perception that her blood was evil) was said to have impaired her capacity to refuse blood transfusion. In contrast, Mr C was found to be mentally competent despite suffering a mental disorder. Even E’s parents were resigned to the fact that because E dreaded food therefore she would be deprived of the right to refuse food by virtue of her being pronounced as mentally incompetent. This sentiment was powerfully captured in their response to Dr Glover’s statement about her incapacity and her AD:[109]

> It seems strange to us that the only people who don’t seem to have the right to die when there is no further appropriate treatment available are those with an eating disorder. This is based on the assumption that they can never have capacity around any issues connected to food. There is a logic to this, but not from the perspective of the sufferer who is not extended the same rights as any other person.

John Coggon, in a commentary on Miss E’s case questioned this point too:[110]

> Worryingly for patients and practitioners, both E’s case and the wider body of jurisprudence in this area fail to clarify quite what patients should do if they wish to execute a fatal advance

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[105] *Re T* above.

[106] Mental Capacity Code of Practice at [4.22].

[107] *A Local Authority v E (by her Litigation Friend of the Official Solicitor), A Health Authority and E’s Parents,* above, at [23], [52], [87].

[108] Ibid, at [52].

[109] Ibid, at [52].

[110] John Coggon “Commentary: Anorexia Nervosa, Best Interests, and the Patient’s Human Right to ‘A Wholesale Overwhelming of Her Autonomy’” (2013) 22(1) Medical Law Review 119 at 127. See also Carolyn Johnston “Advance decision making—rhetoric or reality?” (2014) 34 Legal Studies 497 at 502, 503 critiquing the court’s approach towards the presumption of capacity and the danger with patients such as Miss E who suffered from a medical history of mental disorder seeking to make an AD.

> directive that will, in the end, be respected in situations where the decision is based on reasons or rationales that might be questioned. [I]t is troubling that this point should stand at all, given that in theory a patient's reasons themselves ought not to bear on the assessment.

Another concern relates to the relationship between a person who is detained under the Mental Health Act and their mental capacity under the MCA. E made the AD in October 2011 with the help of a mental health advocate and a solicitor, purportedly when E was mentally competent.[111] The Court appeared to view her committal under the Mental Health Act as one of the factors in a finding of mental incapacity. It seems then that the absence of a mental capacity assessment at the material time, together with the fact that she was placed under the Mental Health Act on the same day for treatment of anorexia suggests that she would not likely be competent under the MCA.[112]

The relationship between the MCA and the Mental Health Act was addressed in the Mental Capacity Code of Practice which clarified that "generally an advance decision to refuse treatment for mental disorder can be overruled if the person is detained in hospital under the Mental Health Act 1983."[113] It happened that E's AD was to refuse food and the committal under the Mental Health Act was for treatment of her refusal to eat. The Court most likely deemed E to have lacked the capacity to make the AD pursuant to her detention under the Mental Health Act. This would gravely undermine the effectiveness of ADs made by patients like E.

E's case demonstrated an aspect of the MCA which was inclined towards a best interest framework prioritising the preservation of life.[114] An advance decision refusing life sustaining treatment can be binding under specified circumstances described above. While the Court recognised the intrusiveness of force feeding and its impact, both physical and psychological on E,[115] if the proposed treatment brings some benefit to E, there is a valid reason to preserve her life.[116] E was unlike KH, who had already become unconscious and incompetent. The solicitor and doctors who came into contact with E had expressed that E was "fully and articulately engaged" despite being incapacitated.[117] This approach challenged the effectiveness of ADs under the MCA and consequently the ability to exercise autonomy under the law.

It also highlighted the influence of a combination of the patient's medical history and current circumstances, together with the lack of mental capacity assessment at the time the AD was made of an inference that the patient lacked the mental capacity to decide at the time the AD was made. E's sudden outbursts, in response to the mention of food, together with displays of wavering thoughts towards her life generally cast

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[111] Ibid, at [64].

[112] Ibid.

[113] Mental Capacity Code of Practice at [9.37] and ch 13.

[114] Ibid, at [140] where the Court found in favour of preserving E's life despite very "weighty factors" concerning treatment risks and benefits for E.

[115] Ibid, at [117], [125], [131], [135].

[116] The Court justified the finding for force feeding E as being "proportionate to a legitimate aim, namely the preservation of life." Ibid, at [122], [125], [132], [137], [138].

[117] Ibid, at [127], [132].

doubt on whether her refusal represented her true wishes. The court therefore tried to gauge, retrospectively, whether the patient was competent at the time of writing the AD. In the absence of evidence about their competence at the time, the Court may draw adverse inferences and find against the validity of the AD.

An example in contrast to E is *Re XB*, a treatment refusal case which satisfied the requirements of a valid AD under ss 24, 25 and 26.[118] The primary care trust brought an application under s 26(4) of the MCA for a declaration that the AD made by XB was valid due to concerns about the circumstances surrounding the signing of the AD. XB suffered from a motor neuron degenerative disease, similar to AK. The Court referred to the evidence of XB's doctor who demonstrated the care and attention in the process of recording the wishes of XB.[119] The Court was satisfied with the evidence of his mental capacity at the time his doctor recorded his AD.

Thus far there have been no cases dealing directly with determining a person's voluntariness in making AD since the adoption of the MCA. The ability to understand the information relevant to the decision is explained in s 3(2) of the MCA. If a person is able to understand an explanation of the information conveyed in a suitable way for the circumstances that he is in, then he is regarded as capable of understanding the information[120] even if such information can only be retained for a short span of time.[121] The cornerstone for the amount of information appears to be the relevancy of the information to the decision and the reasonably foreseeable consequences of "deciding one way or another or failing to make the decision."[122] Relevance could mean if the resuscitation is refused, what would happen to the person who refused it or in a blood transfusion situation, whether there are any available substitutes or just a blanket refusal.

3.2.2.3 The Applicability of the Advance Directives: Scope, Clarity and Subsequent Changes

The question of the applicability of an AD is also considered under the MCA. An AD is inapplicable where the person has withdrawn the decision at the time of capacity, or has created a lasting power of attorney after the advance decision pertaining to the refusal of consent or demonstrated actions which are inconsistent with the advance decision.[123] The AD is equally inapplicable when the treatment refused falls outside of the treatment specified in the AD, or the circumstances specified is absent or that the circumstances have changed which would have affected the person's decision to refuse[124] or that there are reasonable grounds to believe that

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[118] *The X Primary Care Trust v XB and Anor* [2012] EWHC 1390 (Fam).

[119] Ibid, at [17], [18].

[120] MCA 2005 (UK), s 3(2).

[121] Ibid, s 3(3).

[122] Ibid, s 3(4)(a)(b).

[123] Mental Capacity Act 2005 (UK), s 25(1), (2), (3).

[124] Ibid, s 25(4).

circumstances exist which the person failed to anticipate at the time of making the AD and which would have affected his decision had he anticipated them.[125] These requirements, read collectively signify a standard for a person that is equivalent to, or no higher than that of a contemporaneous refusal of treatment and restate conditions already recognised at common law. Additionally, an AD refusing treatment need not necessarily be made in a legal language; hence a person can specify a treatment he wants to refuse in an ordinary, everyday term.[126]

The facts of *Re XB* mirrored *AK*. XB suffered from degenerative motor neuron disease and had been ventilated for the past 8 years, using his eye movements and a communication board to convey his wishes. The English Court of Protection had to decide whether his advance decision ceasing ventilation was valid and binding on the doctors. The hospital brought the application because it was concerned about the circumstances in which the AD was signed[127] and the effect of a review date in the AD; whether the date was intended to be time limited. Theis J examined the application of ss 24, 25, 26 of the MCA concerning advance decision refusing treatment.[128] Apart from the carer's concern, there were no challenges to XB's mental capacity, his understanding of the nature and consequences of the refusal, the information provided to him and the changes in the circumstances which would otherwise undermine his true wishes.[129]

The concern regarding the circumstances was raised by one of the carers who alleged that she did not see XB consent to the AD with his eyes.[130] This concern was however clarified following a hearing.[131] The Court was satisfied that the AD was competently made and had complied with the formalities of the MCA.[132] In respect of the review date, the Court reviewed the evidence by his doctor and a mental capacity coordinator who confirmed that XB had not intended his advance decision to be time limited when he made it.[133] The cumulative effect was that his AD was valid and binding on the doctors. This decision confirmed the common law position prior to the enactment of the MCA in respect of the necessity to establish mental capacity, voluntariness and understanding. It however highlighted a point about AD forms. While the Court observed that while "there is no set form for advance decisions",[134] it highlighted the importance of adhering to the requirements for making ADs refusing life sustaining treatment.[135]

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[125] Ibid, s 25(4).

[126] Mental Capacity Act 2005 (UK), s 24(2).

[127] Ibid, at [21].

[128] ADs refusing treatment that are legally binding are known as advance decision refusing treatment or simply, advance decision under the MCA.

[129] *The X Primary Care Trust v XB and Anor*, above, n 191 at [12], [13], [25], [26].

[130] Ibid, at [22].

[131] Ibid, at [23].

[132] Ibid, at [25].

[133] Ibid, at [27], [28], [29].

[134] Ibid, at [34].

[135] Ibid.

Therefore in respect of ADs refusing life sustaining treatment, any person would have to comply with the requirements so as to be in a position like XB. The Court also noted the availability of standard forms on the internet with “valid until date” and cautioned the need to include such dates.[136] It suggests that including validity date in an AD is immaterial and it shows, once again, that the content and process are more important than the form itself. It can be suggested that since ss 25(6) does not stipulate the “valid until” requirement, failure to put in this date would not be fatal to XB’s case.

The challenge of subsequent changes casting doubts on the continued application of the AD usually arises where there are competing claims in relation to the validity or applicability of the AD. The MCA provides that a person who has capacity can revoke or modify the AD at any time,[137] in whole or in part and need not be in writing.[138] For example, the evidence in the court in AE led the court to arrive at the conclusion that AE’s personal circumstances had changed resulting in a change of mind in keeping with her prior refusal of blood transfusion. AE had not revoked her AD in writing, a condition which was consistent with the MCA. But the provision stipulates that revocation or modification can be done by a person who has capacity. AE had purportedly expressed that she did not wish to die before she became unconscious. It was unclear whether she had capacity at that time to revoke it.

The Mental Capacity Code of Practice recommended regular reviews and updating to the ADs, particularly for ADs that were made a long time ago.[139] In AK, the doctors were able to confirm his refusal on separate occasions and he knew that were he to change his mind about ceasing ventilation, he could do so. *Re N*[140] similarly considered the question of advance decisions under the MCA regarding withdrawing life sustaining treatment and the importance of the feelings and wishes of Mrs N who became incapacitated due to progressive degenerative multiple sclerosis.

Formal Requirements

For ADs refusing life sustaining treatment s 25 of the MCA introduces formal requirements. The AD will apply only if the patient has verified that it applies at all cost and written, signed and witnessed.[141] If those formal requirements are not met, then the AD does not bind the doctors. It is then clear that for example, Ms KH’s prior verbal expressions that she did not want to be dependent on machines would not qualify as a valid AD to refuse consent to reinsert the feeding tube that provided life sustaining

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[136] Ibid, at [35].

[137] Ibid, s 24(3).

[138] Ibid, s 24(4).

[139] Mental Capacity Code of Practice at [9.29], [9.30].

[140] *Re N [2015] EWCOP 76.*

[141] Mental Capacity Act, ss 25(5) and 25(6).

treatment under the MCA. An AD can be withdrawn or revoked in any manner, not necessarily in writing[142] and at any time when the person has the capacity to do so.[143]

Similarly, when applied to the case of Miss T, an advance decision refusing life sustaining treatment must be in writing, a statement verified by T that she had intended it to apply even at the risk of death, signed by T, whose signature must be witnessed. Blood transfusions can be considered as both life sustaining and life saving treatments. T's AD appeared to fulfil these requirements but for her mental capacity. Moreover, she was persuaded to receive transfusion and this potentially signalled an inconsistent conduct with her AD. The surrounding circumstances and especially T's mental capacity would have raised doubts to her AD, rendering it invalid. As such, her AD would be neither valid nor applicable under the MCA.

AK would not be decided differently under the MCA. AK's AD satisfied the capacity, voluntariness and information requirements. It would have been valid under the MCA for refusal of life sustaining treatment because he had verified "to the effect that it is to apply to that treatment even if life is at risk".[144] It complied with the requirements of writing, signing and witnessing. Although it was unknown from the facts whether AK had any lasting power of attorney that would prevent the AD from being treated as valid and applicable under s 25, it would have satisfied the other requirements of a valid AD.[145] The facts of AK appeared to imply that it would be best practice to have a doctor's involvement in the process of recording the AD. The Code of Practice does not mandate but merely recommends people wanting to make ADs to seek advice from doctors, people who are closely involved in their care or organisations that can specifically advise them for particular conditions.[146] Such discussions should be recorded in the patient's medical records.[147]

Re D was decided after the MCA came into force.[148] Mr D, a 55-year-old patient was in a permanent vegetative state following a cardiac arrest during a surgical procedure. He suffered from irreversible brain damage, not responsive to visual or auditory stimuli and was ventilated. Since then, he was fully reliant on the care of others. The Health Trust applied to the court for a declaration that the treatment could be withdrawn lawfully. It emerged that prior to the surgery, he wrote and signed a letter and passed it to his sister-in-law, G.[149] In the letter, Mr D expressed his wishes not to be subjected to invasive, life prolonging treatments or treatments that would considerably reduce his quality of life. Although the Court did not uphold his AD due to non-compliance with the specific requirements in ss 25(5) and 25(6) of the MCA,[150] the Court noted that "Nevertheless, had there been anything to put in the

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[142] Ibid, s 24.

[143] Ibid, s 24(3).

[144] Ibid, ss 24-26.

[145] Ibid, s 25(7).

[146] Mental Capacity Code of Practice at [9.14].

[147] Ibid.

[148] *Re D* [2012] EWHC 885 (COP).

[149] Ibid, at [15].

[150] Ibid, at [16].

balance against the other evidence, D's wishes would have carried very great weight with me."[151]

It can be reasonably postulated then that if he did not suffer from an irreversible medical condition for which treatment is futile, it is unlikely that the court would have authorised the withdrawal of treatment. An example was Miss E (anorexic) where her doctors were of the opinion that there was still hope for E in terms of treatment and despite the invasiveness of force-feeding she was to be treated. Mr D has taken the effort in reducing his refusal for life sustaining treatment in a written, general statement, unaware that it did not comply with the formalities in the MCA. It is clear in this case the form prevailed over the substance of his AD.

His AD did not meet the requirement of witnessing and a statement verified by him that it would apply even if life is at risk. This approach seems to imply that people are expected to be acquainted with the legal language in making the AD, although under the common law there is no specified legal form. This could be one of the necessary acts to ensure a greater likelihood of AD becoming binding. As such, special requirements for ADs refusing life sustaining treatment were introduced to "provide[s] a safeguard that the life of the patient will always be preserved in matters of doubt".[152] Thus, if a person had intended the refusal to apply to life sustaining treatment at the risk of death, this should be "explicitly stated".[153]

Oral or verbal ADs have been considered under the common law in KH, with no certainty. But with the MCA in effect that came with the companion Mental Capacity Code of Practice; this matter has been further clarified. Paragraphs 9.22 and 9.23 of the Code of Practice addressed the confusion about verbal ADs. Particularly, it is advised that "Where possible, healthcare professionals should record a verbal advance decision to refuse treatment in a person's healthcare record. This will produce a written record that could prevent confusion about the decision in the future. The record should include: a note that the decision should apply if the person lacks capacity to make treatment decisions in the future; a clear note of the decision, the treatment to be refused and the circumstances in which the decision will apply; details of someone who was present when the oral advance decision was recorded and the role in which they were present (for example, healthcare professional or family member), and whether they heard the decision, took part in it or are just aware that it exists."

After the coming into force of the MCA, the General Medical Council (GMC) published guidance for end-of-life decision-making for doctors which include references to ADs.[154] It prescribes what doctors must and should do when faced with patients

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[151] Ibid, at [17].

[152] *Who decides? Making decisions on behalf of mentally incapacitated adults: A consultation paper* issued by the Lord Chancellor's Department Presented to Parliament by the Lord High Chancellor by Command of Her Majesty December 1997 (Cm 3803) at [4.26], [4.27].

[153] Ibid.

[154] The GMC Consent: Patients and Doctors Making Decisions Together came into force on 2 June 2008. GMC Treatment and Care towards the End of life: Good practice in decision making was effective on July 2010. Both guidances are available at http://www.gmc-uk.org/. Accessed 10 June 2017.

who refuse treatment and who are planning to make ADs. The GMC guidance emphasised a doctor's role in the making of ADs, and generally in medical decision-making to include family involvement.[155] The Guidance however reminded the doctors that ADs that are valid and applicable are binding, but non-binding refusals must be taken into account in the assessment of the best interest.[156] The particular emphasis and attention to the recording of decisions or refusals as well as reviewing the decisions could be attributed to the need to comply with the requirements under the MCA.[157] On a deeper level, it means that the doctor needs to be sure that those decisions represent the wishes of the patient. Particularly, doctors are encouraged to highlight to the patients the possibility of unforeseen problems during a treatment that they would not be in a position to decide.[158]

Doctor's Liability

No liability is incurred if a doctor treats a person, or withholds or withdraws treatment in accordance with the AD, believing that the AD is valid and applicable.[159] A doctor will be liable if he treats in contravention of a valid and applicable AD.[160] The consequences of liability are not specified and so far the handful of AD cases has not addressed the liability of doctors who refused to comply with a patient's AD or treated a patient contrary to a valid and applicable AD. This gives rise to the question: how can a doctor be satisfied that an AD is valid and applicable? The MCA does not provide any measures to assess, retrospectively if an AD is valid, applicable and thus binding on the healthcare providers. The provisions appear to imply that ADs are made in the presence of a doctor or healthcare provider, similar to a contemporaneous decision. Therefore, presumably, an AD made pursuant to ss 24 to 26 is valid and binding, because a valid and applicable AD is as effective as a contemporaneous decision,[161] while ADs made without the benefit of the said provisions are open to doubt. In addition, the signing and witnessing requirements found in the MCA point towards an inference that all parties – the patient, the doctor and other people involved in the care of the patient—can be confident that it represents the intent of the patient to express a preference in an AD, or at least demonstrates a conscious act on the part of the patient in committing to a decision.

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[155] GMC Treatment and Care towards the End of life: Good practice in decision making at [60], [1].

[156] Ibid, at [68], [69].

[157] GMC Consent: Patients and Doctors Making Decisions Together, 2008 at 25.

[158] Ibid, at 19.

[159] MCA 2005 (UK), ss 26(2) and 26(3).

[160] Ibid, s 25(1)(a)(b).

[161] Ibid, s 26(1)(a)(b).

3.2.3 Conclusion

The MCA prescribes specific requirements for valid and applicable ADs. ADs which comply with the requirements of ss 24, 25 and 26 are binding. ADs refusing life sustaining treatment require compliance with formalities such as writing, signature, witnessing and verified that the AD was intended to apply even at the risk of death. The law does not create new rights that emphasises an individual's autonomy, but merely clarifies decision-making and involves doctors in medical decision-making. While the law still purports to follow a presumption of competence the cases can be interpreted to imply that, when given the chance, courts will prioritise best interests.[162] It can also be suggested that the specific formalities installed for ADs refusing life sustaining treatment implied an approach that err on the side of preserving life whenever doubts arose about such ADs. This meant that unless the person had clearly expressed and verified to the effect that the AD would apply even where life was at risk, the AD would not be presumed to be effective. The MCA changed the common law by putting in place specific requirements for ADs refusing life sustaining treatment and stating that the presumption of capacity applies.

The common law cases, which appear to recognise the importance of autonomy is often stacked against a competing factor—the preservation of life. Thus, only clearly expressed and applicable ADs, made by competent people bind doctors. Otherwise, the person's best interest dictates the course of treatment. Mental capacity often appears to be an important aspect that courts want to know. As such, where mental capacity is often put in issue, a person's incapacity will invalidate the AD in the absence of evidence that the person had competence at the time. Even in situations such as AK and XB, where the patients were found to be competent when they made their ADs refusing further treatment, the hospitals and doctors were uncertain if they could follow the ADs without incurring liability. The MCA had thus clarified the question of doctor's liability in giving effect to ADs with the enactment of s 5.

It is understandable that the doctors are unsure if the wishes remain the true preferences, owing to changes in the personal circumstances or a change of mind. While this is a legitimate consideration, it renders the exercise of autonomy on a higher scale to achieve compared to contemporaneous refusal. Patients such as AK and XB do not constitute the main population of patients in a general sense, because their illnesses are such that death will ensue, unlike patients whose illness is temporary and can be treated using well-established and straightforward treatments, such as food and blood transfusions. Perhaps, the MCA envisions that ADs are only to bind doctors in the event of terminal illness or imminent death but had chosen not to narrow its scope explicitly in the law? If a life can be saved, then the AD can be invalidated to render it inapplicable and not binding. Thus far, patients such as Miss E (the anorexic), Ms T (the bloodletting patient) and KH (reinsertion of feeding tube) had not been able to refuse treatment successfully on grounds of doubts about the

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[162] One of the principles underpinning the MCA was best interest: MCA 2005 (UK), ss 4(4) and 4(6). See also Carolyn Johnston and Jane Liddle "The Mental Capacity Act 2005: A New Framework for Healthcare Decision Making" (2007) 33 J Med Ethics 94 at 96.

validity of their ADs. There is reason to suspect that in cases such as AK and XB their ADs refusing ventilation coincided with the futility of treatment that it would be in their best interest to cease ventilation.

3.3 Case Study II: New Zealand

3.3.1 Overview of the Medico-Legal Framework

New Zealand, as part of the common law tradition, applies the common law in the absence of statute. Its development tends to look to the UK for guidance in respect of legal development and this includes medical law, where a doctor-centred approach prevailed. The triggering point for a slew of reforms to a doctor-centred approach was Sandra Coney and Phillida Bunkle's 1987 article, "An 'Unfortunate Experiment' at National Women's Hospital" in Metro magazine. The article revealed the details of a research project on cervical cancer that had occurred for 20 years in which women had been enrolled without their knowledge or consent, and subsequently impacted the medical profession.[163] The Committee of Inquiry set up by the then Minister of Health and led by Judge Silvia Cartwright made findings about the doctor-patient relationship, and a series of recommendations governing healthcare providers in New Zealand.

Parliament responded to the Cartwright Report by initiating extensive reforms meant to govern the medical profession, for example, the Medicines Act 1994, the Health and Disability Commissioners Act 1994 ('HDC' Act), the Code of Health and Disability Services Consumers' Rights Regulations 1996, known as the Code of Rights, the Health Information Privacy Code 1994 and Health Practitioners Competence Assurance Act 2003. Among these statutory provisions, the Health and Disability Commissioner Act 1994 was the most relevant in terms of reflecting the incorporation of the Cartwright recommendations and especially in illustrating the centrality of patient rights, autonomy and healthcare provider obligations.

The common law right to refuse treatment is enshrined in various laws in New Zealand. For example, the right to refuse treatment is protected in s 11 of the New Zealand Bill of Rights Act 1990. In addition, Right 7(1) of the Code of Rights gives patients the right to make an informed choice and give informed consent to treatment. Patients—known under the Code as "consumers"—have the right to refuse treatment and withdraw their consent to treatment[164] and particularly, the right to use ADs.[165] Such an approach recognises a more proactive and equal involvement by consumers about their healthcare decisions. Choice in this context therefore includes decisions

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[163] Sandra Coney (ed) *Unfinished business*: *What happened to the Cartwright Report* (Women's Health Action, New Zealand, 1993).

[164] Right 7(7) Code of Rights.

[165] Right 7(5) Code of Rights.

to refuse treatment as well as to withdraw consent to treatment.[166] The doctor has the duty to inform the consumer and to obtain consumer consent prior to treatment under the common law.[167]

3.3.1.1 Health and Disability Commissioner Code of Health and Disability Services Consumers' Rights Regulations 1996 ("Code of Rights" or "Code")

The HDC Act serves to promote and protect the rights of health and disability services consumers through an efficient framework of healthcare services accountability.[168] This is achieved through the Commissioner acting on complaints directed at healthcare providers and recommending steps to resolve infringements of patient rights.[169] An advocate acts for health and disability consumers to ensure that consumers know about the provisions of the Code of Rights, assists consumers in ensuring that they give informed consent and to support consumers in the complaints process.[170] Such an approach is designed to empower consumers and support them in exercising their autonomy in medical treatment. The right as consumers of healthcare services is such that any person has the right to make complaints.[171] Essentially, the Code of Rights gives consumers of health and disability services rights and imposes on healthcare providers the corresponding duties, except in limited circumstances, such as on the basis of reasonable actions in relevant circumstances.

The rights in the Code of Rights, ranging from the right to respect, freedom from coercion, expectation to have services of a proper standard, to make informed choice, complain and support are designed to respect the patient's right to bodily integrity and dignity. The Code of Rights is structured in an accessible language, consistent with its aim in empowering consumers[172] and thus supporting efforts in rectifying the power imbalance between healthcare providers and consumers.[173] Pursuant to the reforms arising from the Cartwright Inquiry, a stronger demand for patient autonomy has challenged the dominant paternalistic and beneficent healthcare practices.

The right to make ADs formed part of the reforms pursuant to the Cartwright Report. It enables health and disability consumers to express their wishes about treatment for future incapacity. Consequently, consumers may use advance directives in accordance with the common law. In addition, Right 7(5) does not indicate any

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[166] Code of Rights, cl 4.

[167] *Smith v Auckland Hospital Board* [1964] NZLR 241.

[168] HDC Act 1994, s 6.

[169] HDC Act 1994, ss 14(1)(da), (e), (f), (g).

[170] HDC Act 1994, s 30.

[171] HDC Act 1994, s 31.

[172] Joanna Manning and Ron Paterson "New Zealand's Code of Patients' Rights" in Joanna Manning (ed) *The Cartwright Papers: Essays on the Cervical Cancer Inquiry 1987–1988* (Bridget Williams Books Ltd, Wellington, New Zealand, 2009) at 167.

[173] Ibid, at 165.

specific, formal requirements to make an AD, which is intended to be compatible with existing common law rights. An AD under the Code of Rights is "a written or oral directive by which a consumer makes a choice about a possible future healthcare procedure and that is intended to be effective only when he or she is not competent."[174] Thus, the scope of an AD under the Code of Rights is not limited to terminal illness as is the case with a "living will".[175] This would also imply that the understanding of ADs has evolved from its conventional understanding that was first proposed by Kutner. The expression "choice" is wide enough to include decisions to receive, refuse or withdraw consent to a range of services, such as health or disability services and healthcare procedures.

The common law presumption of mental capacity is reflected in the Code of Rights, where consumers are presumed to be competent in order to make an informed choice.[176] Additionally, the presumption of competence adopted under the Code appears to suggest that it operates in a continuum. Where the patient's competence is reduced, it does not mean that the right to decide is lost, because the patient can still decide on matters which are within the level of competence at that time.[177] Even if the consumer is incompetent, healthcare providers need to take reasonable steps to ascertain the consumer's views and apply those wishes or if the views could not be ascertained, consider the views of people "who are interested in the welfare of the consumer and available to advise the provider".[178]

While there are scholarly discussions on ADs from the social-ethical perspectives, there is a lack of clarity concerning the binding status of ADs in New Zealand.[179] However, given its legislative history arising from the Cartwright inquiry and the legally enforceable provisions, the right to make ADs potentially leads to a binding status under the Code of Rights. As such, an AD, within a framework that promotes and supports autonomy under the Code would most likely be interpreted as binding on the doctor when validly made. It is also essential to note that the Code goes beyond simply acknowledging that consumers have autonomy, but that it supports the notion by *empowering* consumers with the tools to exercise such autonomy.

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[174] Code of Rights, cl 4.

[175] Ron Paterson and PDG Skegg "The Code of Patients' Rights" in PDG Skegg and R Paterson (eds) *Medical Law in New Zealand* (Brookers Ltd, Wellington, 2006) at 45.

[176] Right 7(2) of the Code of Rights.

[177] Right 7(3) of the Code of Rights.

[178] Right 7(4) of the Code of Rights.

[179] Sam McMullan "Advance Directive" (2010) NZFLJ 359; Cordelia Thomas "Refusal of medical treatment by way of advance directives" (2001) 3 NZFLJ 233; Pauline Wareham "New Zealanders making advance directives: A discourse analysis" (Master in Health Science Thesis, Auckland University of Technology, 2005); Phillipa J Malpas "Advance Directives and Older People: Ethical Challenges in the Promotion of Advance Directives in New Zealand" (2011) 37 Journal of Medical Ethics 285.

3.3.1.2 New Zealand Bill of Rights Act ("Bill of Rights Act") 1990

The idea for a Bill of Rights Act 1990 was raised on the basis of improving the system of government.[180] The White Paper envisioned that the Bill of Rights Act would establish a minimum standard of governance that the state would abide by and the court would enforce.[181] The drafters of the Bill of Rights Act referred to the International Convention on Civil and Political Rights (ICCPR) and the Canadian Charter of Rights and Freedoms.[182] The White Paper considered whether the Bill of Rights should be entrenched.[183] In the draft version, the Bill was given supreme status.[184] However following public consultations, it was not entrenched legislation because New Zealand was not yet ready for a legal system which empowered the courts to strike down legislation.[185]

The right to refuse treatment in Right 7 of the Code of Rights had already been recognised in s 11 of Bill of Rights Act where "everyone has the right to refuse to undergo any medical treatment." The right to refuse medical treatment is framed in a wider context of recognising the fundamental rights and liberties in a democratic society, and in compliance with the binding obligations as party to the ICCPR.[186] The explicit provision given to the right to refuse medical treatment is an endorsement of the right to refuse contemporaneously, and can be inferred to extend to the future. However, this right is not absolute because it is not a supreme law and can be limited by other laws.[187] In practice, the right to refuse treatment recognises an individual's personal autonomy and respect for bodily integrity.[188]

Section 11 of the Bill of Rights Act originated from the atrocities of medical experimentation on human subjects. The right to refuse treatment envisioned under s 11 of the Bill of Rights is to protect the autonomy of the individual from becoming the "non-consensual object" of another person and this means that even if the decision is considered a "bad" one, or if it leads to death, such freedom should not be curtailed.[189] Andrew and Petra Butler, commenting on s 11 framed this right within

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[180] *A Bill of Rights for New Zealand: A White Paper* (Wellington, New Zealand, 1985) at 5.

[181] Ibid, at [9.1].

[182] Ibid, at 65. But with major departures from the ICCPR to suit the New Zealand context: at [10.12].

[183] Ibid, at 53, [7.10], 57, 58.

[184] Ibid, at 66.

[185] (10 October) NZPD 13039; (21 August) NZPD 3760.

[186] Ibid, at Preamble.

[187] Ibid, ss 4, 5.

[188] The Guidelines on the New Zealand Bill of Rights Act 1990: A Guide to the Rights and Freedoms in the Bill of Rights Act for the Public Sector http://www.justice.govt.nz/policy/constitutional-law-and-human-rights/human-rights/domestic-human-rights-protection/about-the-new-zealand-bill-of-rights-act. Accessed 19 June 2017.

[189] Andrew Butler and Petra Butler *The New Zealand Bill of Rights Act: A Commentary* (LexisNexis NZ Ltd, Wellington, 2005) at 268. 270; Ron Paterson construed s 11 as wide enough to include refusal of live saving treatment, see Ron Paterson "The Right of Patients to Refuse Medical Treatment" (19 August 1991) NZ Doctor at 33.

the context of a person's capacity to refuse, the information required to exercise the refusal and whether the patient can refuse life sustaining treatment.[190] In respect of a person's mental capacity, Butler concluded that in order to give full effect to this provision, a mentally incompetent person falls within the ambit of having the right to refuse treatment, where other people can consent on behalf of the patient.[191] If there is misinformation that offends the person's autonomy then that is an infringement of s 11.[192] This interpretation of s 11 does not plainly suggest that it operates only in the context of a refusal that is carried out contemporaneously. It construed the right to refuse in a broad way where the state can intervene in specific circumstances only, for example in emergency situations or in cases involving children. This interpretation is premised on the aims of the Bill of Rights Act which is to protect the individual's autonomy. This interpretation potentially means that the right to refuse that is intended to operate in the future, (such as the case of an AD) will fall under the ambit of protection of s 11, consistent with the protection of autonomy.

Although the right to refuse treatment has been interpreted as a right available to conscious individuals whether they are competent or mentally incompetent,[193] "everyone" here has been held to refer to competent persons.[194] Rishworth has interpreted this right to be broader, encompassing individuals who are unconscious, although cases have construed the right to refuse treatment as available to individuals who are competent to consent.[195] However Rishworth interpreted s 11 together with s 10 concerning the right not to be subjected to medical experimentation that encompasses a right to refuse and a right not to be medically treated without consent.[196] The right to refuse treatment applies to individuals professing the Jehovah's Witness faith.[197] Rishworth was right to note that the right to refuse applies regardless of the religious beliefs, and this right does not hinge upon religious belief.

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[190] Andrew Butler and Petra Butler *The New Zealand Bill of Rights Act: A Commentary* (LexisNexis NZ Ltd, Wellington, 2005) at 267.

[191] Ibid.

[192] Ibid, at 270.

[193] Ibid, at 255.

[194] Andrew Butler and Petra Butler *The New Zealand Bill of Rights Act: A Commentary* (Wellington, LexisNexis NZ Ltd, 2005) at [11.6.5] and [11.8.1]. *A Bill of Rights for New Zealand: A White Paper* (Wellington, New Zealand, 1985) at [10.5]; *Re G* [1996] 2 NZLR 201 (HC). A recent New Zealand decision has also confirmed this interpretation: *Chief Executive of the Department of Corrections v All Means All* [2014] NZHC 1433.

[195] Ibid, at 256; the cases referred to were *Re S* [1992] 3 NZLR 363, 374 and *Re G* [1997] 2 NZLR 201.

[196] Ibid.

[197] Paul Rishworth and others *The New Zealand Bill of Rights* (OUP, South Melbourne, Victoria, New York, 2002) at 206.

3.3.1.3 Protection of Personal and Property Rights Act 1988 (Amended 2007) ("PPPRA")

The PPPRA is relevant to the context of the appointment of enduring power of attorney for personal care and welfare[198] in terms of the scope of the powers that an attorney has for refusing treatment on behalf of an incompetent person. A presumption of competence applies for purposes of exercising personal rights[199] and for appointing an enduring power of attorney.[200] What constitutes mental incapacity is read in the context of appointing a power of attorney.[201] An attorney has no power to act in major personal care decisions (decisions that implicate the health, wellbeing or enjoyment of life of the donor) unless a health practitioner has certified that the donor is mentally incapable or the court has determined that the donor is incapable mentally.[202] Assuming that a donor appoints an attorney in the AD to implement the AD refusing treatment that potentially causes death, questions arise as to whether the attorney would be able to execute the AD. Setting aside questions regarding the AD's validity, the attorney may be restricted to apply the AD. The framework upon which the PPPRA operates is the best interest of the donor.[203] Section 18 limits the power of welfare guardians to refuse standard life saving medical treatment.

In addition, life saving medical treatment may involve intrusive or extraordinary measures. It can range from resuscitation to ventilation support where the aim is to save the person's life or to prevent serious damage. Although s 18 expressly forbids welfare guardians to refuse standard life saving medical treatment, it may not prevent them from agreeing with the doctors that standard life saving treatment should not be continued. This means that if a doctor, in the doctor's professional view opines that

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[198] PPPRA 1988, Part 2: welfare guardians; Part 9: enduring power of attorney.

[199] PPPRA 1988, s 5 Presumption of competence: "For the purposes of this Part of this Act, every person shall be presumed, until the contrary is proved, to have the capacity—(a) to understand the nature, and to foresee the consequences, of decisions in respect of matters relating to his or her personal care and welfare; and (b) to communicate decisions in respect of those matters.".

[200] PPPRA 1988, s 93B Presumption of competence: "(1) For the purposes of this Part, every person is presumed, until the contrary is shown,—(a) to be competent to manage his or her own affairs in relation to his or her property: (b) to have the capacity—(i) to understand the nature of decisions about matters relating to his or her personal care and welfare; and (ii) to foresee the consequences of decisions about matters relating to his or her personal care and welfare or of any failure to make such decisions; and (iii) to communicate decisions about those matters.

[201] PPPRA 1988, s 94 Interpretation: "(2) For the purposes of this Part, the donor of an enduring power of attorney is mentally incapable in relation to personal care and welfare if the donor—(a) lacks the capacity—(i) to make a decision about a matter relating to his or her personal care and welfare; or (ii) to understand the nature of decisions about matters relating to his or her personal care and welfare; or (iii) to foresee the consequences of decisions about matters relating to his or her personal care and welfare or of any failure to make such decisions; or (b) lacks the capacity to communicate decisions about matters relating to his or her personal care and welfare.".

[202] PPPRA 2007, s 98(3).

[203] PPPRA 2007, s 98A on the exercise of enduring power of attorney in relation to personal care and welfare in which the overarching principle of the donor's best interest applies.

treatment should be discontinued, the welfare guardians can agree with the doctor's view.

While donors are free to make ADs as a form of personal care decision and appoint attorneys to act for them, the power is limited because an attorney is not permitted to refuse consent to life saving treatment that is proposed for the donor.[204] This approach stands in contrast to the Bill of Rights Act and the Code of Rights because it operates on a best interest framework in the context of decision-making for the mentally incompetent person in a wider sphere; which is not necessarily medical treatment only. We take a look at the judicial approaches towards treatment refusals in New Zealand.

3.3.1.4 Judicial Approaches Towards Treatment Refusals and ADs

The right to refuse treatment and to have treatment withdrawn at the risk of death is recognised and accepted in New Zealand. Cases involving ADs specifically were a rarity, until the decision of *All Means All*,[205] which sheds light on the approach towards ADs. *Re MP* provides a brief mention of AD where the court encouraged patients to make an appropriate AD whilst in a relative state of wellness.[206] Some cases involving the withdrawal or withholding of treatment which touched on the patient's right to refuse and withdraw consent to treatment, is *Re G.*[207] In *Re G,* Mr G suffered from severe brain damage with no prospect for recovery following a motor accident. His next of kin applied to the court to terminate his life support, on the basis that G would not want to be kept alive in that condition.[208] The Court accepted their evidence even though Mr G had not clearly expressed any wishes as to what he would like in the circumstances that had arisen. In arriving at the decision, the Court adopted the best interest approach, over the substituted judgment principle, with weight given to "the likely wishes of the patient and the views of his family and medical carers".[209] This case illustrated the primacy of autonomy and indirectly

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[204] PPPRA 2007 s 99A: Attorney's duty to consult "(1) When acting under an enduring power of attorney, the attorney must, as far as is practicable, consult—(a) the donor and; (b) in relation to any particular matter, any person specified in the enduring power of attorney to be consulted, generally, in respect of matters of that kind, or in respect of that matter. (2) An attorney acting under an enduring power of attorney in relation to the donor's personal care and welfare may, subject to any consultation under subsection (1), have regard to any advance directive given by the donor except to the extent that the directive would require the attorney to act in a manner contrary to section 98(4).".

[205] *Chief Executive of the Department of Corrections v All Means All* [2014] NZHC 1433.

[206] *Re MP* [1997] NZLFR 978; also by the New Zealand Law Society in a published pamphlet (September 2011) "Powers of Attorney: Do the Right Thing" at 7; a distinction is made between advance directives/living wills and enduring power of attorney. The enduring power of attorney is legally binding while advance directives and living wills are merely expression of wishes which may not have binding legal effect.

[207] *Re G* [1996] 2 NZLR 201 (HC).

[208] Ibid, at [2].

[209] Ibid, at 202.

accepted the value of roles played by family and close friends in the absence of clearly expressed wishes.

In respect of the case of *All Means All*[210] a prisoner's hunger strike refusing food and liquid was upheld to bind the carers at some future point of time. His desire in refusing food and liquid meant that he would resume his strike each time he became incapacitated and then treated by the hospital. The prison authority and the hospital sought clarifications from the court regarding their duties towards the prisoner's refusal of food and liquid. Following assessments from four psychiatrists, the Court ruled that he was mentally competent and knew the consequences of his refusal, and as such, his refusal would bind the doctors contemporaneously and in the future as an AD once he became incapacitated as a result of the hunger strike.

The cases discussed above appeared to suggest that a prior preference of treatment refusal as expressed by the person (as in the case of Mr All Means All) or communicated by the family members (as in the case of Mr G) would bind the doctors. Both cases supported the established right to refuse treatment under the New Zealand law.

3.3.1.5 HDC Opinions

Aside from judicial decisions, the Health and Disability Commissioner issues opinions in respect of alleged breaches of the Code of Rights by healthcare providers. These opinions nonetheless carry weight by providing guidance on the application of the Code of Rights in particular circumstances. This includes dealings with some aspects of ADs, for example in cases of residents in nursing homes.

An example of an opinion issued by the Health and Disability Commissioner concerned a complaint against Dr C for not complying with an alleged AD made by Mrs A.[211] Mrs A suffered from Huntington's disease and had refused institutionalisation. The Commissioner recognised Mrs A's ability to consent to and refuse treatment.[212] However, the Commissioner found that Mrs A's remarks were not a valid AD because she had not been properly informed of the nature and consequences of her refusal to be institutionalised and was unaware of the likely effect of her illness. This opinion highlights the issue of whether a person who makes an AD must be informed in order to be valid. There are differing views in the literature on the need to be informed in consenting to, and refusing treatment contemporaneously or in advance.[213] The

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[210] *The Chief Executive of the Department of Corrections & Canterbury District Health Board v All Means All* [2014] NZHC 1433.

[211] Opinion 11HDC00647 at [147]–[152].

[212] Ibid, at [158].

[213] The question of informed refusal was considered by the Queensland Law Reform Commission, with special reference to the common law cases on ADs such as *Re T (adult: refusal of treatment)* and *Malette v Shulman*. See further Queensland Law Reform Commission *A Review of Queensland's Guardianship Laws Report 67* (Queensland Law Reform Commission, September 2010); other scholarly research includes Daniel M Avery "Summary of Informed Consent and Refusal" (Summer 2009) 6 American Journal of Clinical Medicine 28 at 29; Donald T Ridley "Informed Consent, Informed Refusal, Informed Choice—What Is It That Makes A Patient's Medical Treat-

Canadian case of *Malette v Shulman*[214] is an example where a patient need not be informed for an AD to be upheld as valid. In a contemporaneous treatment refusal, a patient has the right to be informed but if the patient refuses to be informed there is the opportunity to verify such refusal. The difficult aspect of ascertaining whether the patient has been informed about the nature and consequences of refusal in making the AD is the absence of opportunity to retrospectively verify the refusal.

In the context of ADs, it is preferable that a person is informed of the nature and consequences of refusing treatment. In the event the patient chose to waive the right to be informed, such refusal could be recorded as evidence that the patient had so decided. It is also possible that the patient may have been informed but has elected not to act on the information, or has decided to proceed with the refusal after considering the information. This position is likely to address the differences between contemporaneous refusals and ADs.

In another HDC opinion, the Commissioner opined that an AD would have been valid if it had been signed by a competent resident and not by someone else on the resident's behalf.[215] Similarly, in a separate decision the Commissioner found that the two ADs purportedly made by the resident, first refusing resuscitation but a later AD requesting greater intervention could potentially bind the nursing home if they were made by the consumer.[216] The decision did not reveal whether the AD was made on a pre-printed form produced by the nursing home or whether it had been explained to or signed by the resident. These opinions and cases showed that should an AD dispute occur in New Zealand, the AD would comply with the requirements of making a contemporaneous refusal, in accordance with the rights under the Code of Rights, an interpretation consistent with the aims of the Bill of Rights and the Code of Rights.

3.3.2 The Medical Professional's Attitude Towards ADs

The New Zealand Medical Council had previously recommended legislative changes in laws governing living wills, enduring power of attorneys, substituted judgement

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ment Decisions Informed?" (2001) 20 Med & L 205; Howard Brody and Ruth Jepson "Clinical Case: Informed Refusal Ethics" (2006) 8 Journal of the American Medical Association 24; Thomas M O'Neil "Truman v Thomas: The Rise of Informed Refusal" (1980–1981) 8 Pepp L Rev 1067; Ellen A Kold and Nancy Ramseyer "Truman v Thomas: Informed Refusal in Simple Diagnostic Testing" (1980–1981) 14 UC Davis L Rev 1105; William C Knapp and Fred Hamilton "'Wrongful Living': Resuscitation As Tortious Interference With A Patient's Right To Give Informed Refusal" (1991–1992) 19 N Ky L Rev 253; Gerard V Bradley "Does Autonomy Require Informed and Specific Refusal of Life-Sustaining Medical Treatment?" (1989–1990) 5 Issues L & Med 301; Fenella Rouse "Does Autonomy Require Informed and Specific Refusal of Life-Sustaining Medical Treatment?" (1989–1990) 5 Issues L & Med 321.

[214] *Malette v Shulman* (1990) 72 OR (2d) 417.

[215] Opinion 11HDC00512 at [78], [120], [122], [142].

[216] Opinion 09HDC01641 at [176], [177].

or best interest legislations.[217] The National ACP Cooperative was launched in an effort to promote advance care planning awareness in New Zealand. The Cooperative is "a national collective of passionate like-minded people" aimed at designing and implementing ACP in New Zealand and to provide among others, uniformed, consistent practices across district health boards in ACP practices.[218] It strives to work with agencies to further its aims within New Zealand's legal and ethical framework.[219] The National Ethics Advisory Committee, in its guide on Ethical Challenges in Advance Care Planning supports the notion that doctors play a role in guiding patients in their AD decision-making process.[220] The Committee identified the challenges and solutions for ACP practices that particularly enable autonomy in the ACP process.[221] While ACP recognised the importance of exercising autonomy for future incapacity, it is unclear how this autonomy can be exercised if it is unclear what the status of these documents would be.

The notion of patients as consumers within the Code of Rights sits uncomfortably within the medical professionals. The term "consumer" instead of "patient" in the spirit of empowering patients,[222] signifies a stronger position with rights in accessing and using healthcare services. In contrast, the NZMA Code of Ethics[223] refers to "patients", rather than consumers or any other name, because in their view it "reflects accurately the nature of the relationship between a doctor and the person seeking help."[224] Referring to patients as consumers is unlike that of the other legislation concerning healthcare, for example the English Mental Capacity Act where healthcare users are commonly known as patient, as is the case in Canada. Reference to the term "patient" suggests the conventional understanding of a therapeutic relationship where doctors act in the best interest of the patient at all times. Healthcare users as

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[217] Bioethics Research Centre University of Otago *Persistent Vegetative State and the Withdrawal of Food and Fluids: A Report for the Medical Council of New Zealand* (February 1993) at 29. The suggested provision reads as follows: cl 3.3 of the World Health Declaration on the Promotion of Patient's Rights in Europe 1994: "[W]hen a patient is unable to express his or her will and a medical intervention is urgently needed, the consent of the patient may be presumed, unless it is obvious from a previous declared expression of will that consent would be refused in that situation.".

[218] "The Advance Care Planning Cooperative" (2014) Advance Care Planning Cooperative http://www.advancecareplanning.org.nz/aboutACP/#here. Accessed 8 October 2017.

[219] Ibid.

[220] National Ethics Advisory Committee "Ethical Challenges in Advance Care Planning" (Wellington, Ministry of Health, 2014) at 2. The document was framed as a guide for health professionals with a focus on ACP in the geriatric, oncology, end of life care and services for people with long term health conditions context.

[221] Ibid, at 6.

[222] The Code defines a consumer as "a health consumer or a disability services consumer; and, for the purposes of rights 5, 6, 7(1), 7(7) to 7(10), and 10, includes a person entitled to give consent on behalf of that consumer.".

[223] Code of Ethics for the New Zealand Medical Profession www.nzma.org.nz. Accessed 4 October 2017. The Australian Medical Council adopted similar position and encouraged the involvement of doctors in participating in advance care planning with the patients; see Australian Medical Council Good Medical Practice: A Code of Conduct for Doctors in Australia (July 2009) at 13.

[224] Code of Ethics for the New Zealand Medical Association at 3.

"consumers" under the Code connote a relationship that is patient-driven and market-oriented, with consumers having the power not only to exercise their choices for their services from a range of options available, but to request for demands to be met by healthcare professionals. It is unsurprising that there was resistance to the continued status of consumers as having rights only while healthcare providers assumed responsibilities and obligations to facilitate the fulfilment of consumer rights.[225]

3.3.2.1 New Zealand Medical Association Code of Ethics and Position Statement on AD

The New Zealand Medical Association (NZMA) has come a long way since its formation was first proposed by Professor Millen Coughtrey of Dunedin.[226] However the NZMA was only established ten years later in 1886 after Professor Coughtrey's proposal.[227] Initially, its purpose was to provide a platform for medical professionals to voice their opinions on issues of medical politics.[228] Prior to establishing the NZMA, the medical fraternity had adopted a code of ethics in 1887 which was modelled on the code of ethics in England in 1803, derived from the Hippocratic Oath.[229]

The NZMA recognises that while patients have rights under the Code of Rights, doctors have professional and ethical constraints in treating their patients.[230] Thus it advocates a partnership model of decision-making in a therapeutic relationship rather than the pure autonomy model.[231] The NZMA's first Principles of Ethical Behaviour prioritises patient health and wellbeing, followed by respecting patient rights.[232] The NZMA Code of Ethics 2014 recommends that "doctors should be prepared to discuss and contribute to the content of advance directives and give effect to them."[233] It is clear that doctors would like to be involved in the decision-making process of ADs, a position similar to the Australian Medical Association[234] and echoed by the NZMA

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[225] *A Review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights: Report to the Minister of Health* (June 2004) at 21.

[226] RE Wright-St Clair *A History of the New Zealand Medical Association: the first 100 years* (Butterworths of New Zealand (Ltd) Wellington, 1987) at 6–7.

[227] Ibid.

[228] Ibid, at 8.

[229] Ibid, at 51.

[230] Code of Ethics for the New Zealand Medical Association (2013) at 183–184 referred to a doctor's accountability to patients, and that patients have the legal right to services under the Code that comply with ethical standards such as the Code of Ethics. The Australia Medical Association shared similar view: Australian Medical Association: The Role of the Medical Practitioner in Advance Care Planning—2006 at [3.4].

[231] Code of Ethics for the New Zealand Medical Association (2013) at 2.

[232] Ibid, at 4.

[233] Ibid, at 7.

[234] Australian Medical Association: The Role of the Medical Practitioner in Advance Care Planning (2006).

Position Statement on ADs. The NZMA approach towards ADs can be said to be emphasising a doctor's role in making anticipatory treatment decisions, together with family, friends and other people that the patient wished to be involved in.[235]

There are several reasons to support the inference that the NZMA prefers non-binding advance statements and advocate the practice of ACP. Firstly, the NZMA expressed their caution about legally binding ADs, due to disagreement with professional opinions about providing clinical care that differs from the AD and medical permutations.[236] It highlighted the unanticipated changes in personal or medical circumstances and treatment potentials that an AD cannot adequately capture.[237] These concerns relate to the time when an AD is sought to be implemented, taking into account the subsequent changes that potentially occur. They viewed ADs as an on-going process of communication and reflection between the patient and doctors.[238] Secondly, it accepts doctors to be "under no absolute legal obligation to follow an advance directive which is not consistent with good medical practice."[239] Thus, ADs do not necessarily bind doctors. Thirdly, it supports the view that "doctors should be under no obligation to follow an advance directive to which they hold a conscientious objection or see the action as unethical".[240]

Despite recognising the complexities of ADs, the NZMA appears to accept that ADs "would be particularly useful" in limited circumstances—a patient who is in the final stages of a terminal illness and where death is imminent, a patient who is in a persistent vegetative state or coma or where the patient has no hope of recovery.[241] The fact that they particularly highlighted these three circumstances may suggest that in their view, under these situations, continued treatment would be futile or would not be in the patient's best interest. Therefore where a patient has expressed a prior preference refusing treatment under any of these circumstances, it will be consistent with good medical practice, and would most likely be binding. The three reasons identified above also seem to incline towards a consideration of what is best for the patient according to medical practice. Despite their reservations about ADs, the NZMA called "for the development of clear, nationally consistent guidance for

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[235] NZMA Position Statement on Advance Directives at [5].

[236] See for example the NZMA Position Statement on Advance Directives at [10]: "Recognises that advance directives may play an important role in the health care process and can enhance patient self-determination, however, the direct application of an advance directive under certain circumstances may pose the following serious ethical and clinical challenges to the health care team: (a) The circumstances that existed at the time the advance directive was made may have changed. It may then be impossible to determine the extent to which the advance directive may still apply. Health care decisions arising from an advance directive are based on the information relevant to the medical condition (if any) and treatment options available, as well as the patient's attitude and values around health care, at the time the advance directive was made.".

[237] NZMA Position Statement on Advance Directives.

[238] Ibid, at [4].

[239] Ibid, at [10].

[240] Ibid, at [11].

[241] Ibid, at [8]. The Australian Medical Association echoed similar position: Australian Medical Association: The Role of the Medical Practitioner in Advance Care Planning (2006).

the preparation, notification and storage of advance directives, including consistent pro-formas."[242]

The ambivalence towards accepting legally binding AD is much more pronounced within the medical professionals. While the Cartwright Inquiry may have, on a policy and legislative level, influenced the shift from doctor-centric practices to patient-centred approach, this influence may have yet to permeate the entire medical profession. However, the message is clear that in the process of making ADs, doctors would like to and should participate in the process with the patient.

3.3.3 Conclusion

New Zealand's medico-legal history, which impacted its medical practice and current developments surrounding treatment refusal cumulatively, points towards an approach where contemporaneous treatment refusal is accepted as binding. However, this acceptance cannot be said to be clearly extended to ADs. For example, although Right 7(5) in the Code of Rights permits consumers to make ADs it is nowhere clear if it will bind healthcare providers. There have been no cases dealing with ADs directly other than *Mr All Means All* which was a contemporaneous refusal that was intended to become an AD. The HDC opinions seem to suggest that if there was a clear AD it would have been binding. The NZMA recognises that ADs would be particularly useful in certain specified situations, but appears to prefer ACP to legally binding ADs.

This situation gives rise to two possibilities – ADs can be legally binding, similar to contemporaneous refusal based on the principle of autonomy or ADs are not likely to be legally binding because they are unlike contemporaneous refusals. These two possibilities give rise to different implications. In respect of the first possibility, New Zealand's strong patient-centric approach, in which autonomy is a key feature from the Cartwright legacy, provides strong support for ADs to be legally binding. The effect is that either the courts will adopt an interpretation which favours patient autonomy, dispensing the need to clarify Right 7(5) or, the uncertainty in the regulatory framework provides the opportunity to construct an approach to achieve legally binding ADs consistent with a strong patient-centred approach. It can be said that the legal environment which permits the realisation of patient rights provides a foundation for signifying that ADs can be legally binding in New Zealand based on the recognition of patient autonomy.

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[242] Ibid, at [12].

3.4 Case Study III: Canada

3.4.1 The Position of ADs in Canada

There are variations in the attitudes of physicians and patients in studies conducted in Canada. For example, in Quebec, a study aimed at identifying both the patients' and healthcare professionals' attitudes towards ADs revealed that while patients view ADs as securing their autonomy, physicians view them unfavourably, preferring beneficence in medical treatment.[243] A report on end-of-life decision-making patterns in Canada[244] stated that "healthcare providers are generally supportive of the use of ADs."[245] The report indicated that ADs are beneficial for dispute resolution when conflicts arise regarding treatment options, and are useful as a communication vehicle among patients, families and their physicians.[246] Common concerns raised regarding the use of ADs include vagueness in the terms of the ADs, clinical recommendations which differed from the instructions in the ADs, and the level of informed-ness on the part of patients concerning the proposed treatment.[247] Meanwhile, a study in Ontario revealed that physicians are supportive of ADs but only a small cohort discussed it with their patients.[248] A majority of these physicians had never used ADs for treatment of incompetent patients and for those who did, more than half reported that they ignored the terms of the ADs.[249]

The Canadian Medical Association Code of Ethics served as an ethical guide for doctors. Its guideline recommends that doctors "respect the intentions of an incompetent patient as they were expressed (e.g., through a valid advance directive or proxy designation) before the patient became incompetent."[250] In its policy statement concerning ADs, the Association recognised that the patient is the ultimate decision-maker possessing the right to consent to or refuse treatment lies with the patients, and in this spirit, mandates doctors to help patients in making ADs and to honour the AD unless there are reasonable grounds to depart from the terms of the AD[251] such as where the AD no longer represents the patient's wishes or the patients did not fully

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[243] Danielle Blondeau and others "Comparison of patients' and health care professionals' attitudes towards advance directives" 1998 (24) Journal of Medical Ethics 328.

[244] Udo Schüklenk and others "The Royal Society of Canada Report: End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making" (2011) 25 (S1) Bioethics 1.

[245] Ibid, at 15.

[246] Kelner M, Bourgeault IL, Hébert PC, Dunn EV "Advance directives: the views of health care professionals" 1993 148 (8) Canadian Medical Association Journal 1331.

[247] Ibid.

[248] Hughes DL, Singer PA. "Family physicians' attitudes towards advance directives" 1992 146 (11) Can Med Assoc J 1937.

[249] Ibid.

[250] Canadian Medical Association Code of Ethics 2004 at [28].

[251] Canadian Medical Association Policy Summary "Advance Directives for Resuscitation and other Life saving or Sustaining Measures" (1992) 146 (6) Can Med Assoc J 1072A at [1].

understand the implications of the decision at the time it was made.[252] It recognised the limits of ADs where the terms were either too specific or too general so as to render the AD inapplicable. It recommends that doctors participate in the process of creating ADs with their patients, advising them of the AD's limitations, putting the wishes into writing as well as identifying proxy decision-makers as one way of clarifying the ADs as needed.[253] This policy statement indicates that the Association recognised the importance of making valid ADs as a means to express their wishes in the event of future incapacity and actively encourages doctors' involvement in the process.

The Canadian legal framework is underpinned by the Constitution Act 1982 which contained the Charter of Rights and Freedoms ("Charter of Rights"). Its constitutional status is distinct to the New Zealand Bill of Rights Act. Unlike the latter, the Charter of Rights is a supreme law of the land which invalidates other laws that violate the rights guaranteed under the Charter of Rights.[254] The Bill of Rights Act, in contrast is an ordinary statute which does not enjoy a superior status. It only provides for an interpretation that is consistent with the other laws. The Charter of Rights and Freedoms "guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society." The right to refuse treatment is construed in the spirit of the Charter of Rights and the rights contained therein.

For example, in *Fleming v Reid*[255] the Ontario Court of Appeal upheld a psychiatric patient's refusal of future treatment in an AD while mentally competent. The right to refuse treatment was protected under s 7 of the Charter of Rights which trumped the provisions of the Ontario Mental Health Act 1987. Similarly, the Supreme Court in *Starson v Swayze*[256] upheld the refusal of a bipolar disorder patient who refused to consent to treatment for his mental disorder on the basis that he was mentally competent to refuse as his exercise of autonomy. These decisions can be construed as representing the Courts' interpretation of the right to refuse treatment as constituting the fundamental liberty rights guaranteed under s 7 of the Charter of Rights.[257] Consequently it can be implied that the right to autonomy is protected.

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[252] Ibid, at [2].

[253] Ibid, at [1], [3] and [4].

[254] s 32(1) of the Charter of Rights.

[255] *Fleming v Reid* (1991) 4 OR (3d) 74 (Ont CA).

[256] *Starson v Swayze* [2003] 1 SCR 727 (SCC).

[257] See Martha Jackman "The Implications of Section 7 of the Charter for Health Care Spending in Canada" (Commission on the Future of Health Care in Canada, October 2002) at 4.

There is no federal legislation governing ADs; as such each province and territory created various laws governing the same.[258] ADs are more commonly known as personal directives in Canada.

3.4.2 *Validity of Advance Directives: Capacity, Voluntariness and Understanding*

Most of the Canadian statutes use an age-based threshold for determining a person's mental capacity as one of the pre-requisites for making an AD.[259] There is a rebuttable presumption of mental capacity for the purpose of making ADs, which follows that of the age threshold.[260] Apart from mental capacity, there are specific requirements before an AD can bind doctors[261] such as in writing, signature, date and witnessing. Further, if there are any inconsistencies between an instruction for care and the terms contained in the AD, the latter prevails, showing that ADs are given primacy.[262] However, the court still has the power to declare an AD invalid if there is reason to suggest that the person was incapable of consenting to the treatment or if the AD is in conflict with the current wishes of the person,[263] similar to the English position.

A presumption of effectiveness is a distinct feature in some Canadian laws; a provision which is absent in the UK MCA. This presumption assures the maker that unless there is evidence to the contrary, the validity will not be questioned.[264] A presumption of mental capacity applies in all the laws. The laws generally refer to capacity as the ability to understand the nature and effect of the decision,[265] which is similar to the UK. The presumption can be rebutted if there is evidence to the

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[258] Health Care (Consent) and Care Facility (Admission) ActRSBC 1996 c 181, Personal Directives Act 2000 RSA c P-6, Advance Health Care Directives Act 1995SNL c A-4.1, Personal Directives Act 2005 SNWT c 16, Personal Directives Act 2008SNS c 8, Consent to Treatment and Health Care Directives Act 1988 PEI c C-17.2, An Act respecting end-of-life care Bill 2014 (52) c 2 (Quebec), the Health Care Directives and Substitute Health Care Decision Makers Act 1997 S c H-0.001, the Health Care Directives Act 1992 CCSM c H27.

[259] Ibid.

[260] Health Care (Consent) and Care Facility (Admission) Act RSBC 1996 c 181, Personal Directives Act 2000 RSA c P-6, Advance Health Care Directives Act 1995SNL c A-4.1, Personal Directives Act 2005 SNWT c 16, Consent to Treatment and Health Care Directives Act 1988 PEI c C-17.2, An Act respecting end-of-life care Bill 2014 (52) c 2 (Quebec), the Health Care Directives and Substitute Health Care Decision Makers Act 1997 S c H-0.001, the Health Care Directives Act 1992 CCSM c H27; Health Care Consent Act 1996 SO c2.

[261] For example, Quebec established specific requirements before the AD can legally bind doctors: Explanatory note and An Act respecting end-of-life care Bill 2014 (52) c 2 (Quebec) s 1.

[262] An Act respecting end-of-life care Bill 2014 (52) c 2 (Quebec), s 62.

[263] Ibid, s 61.

[264] Advance Health Care Directives Act 1995 (NL), s7.

[265] Health Care (Consent) and Care Facility (Admission) Act RSBC 1996 c 181, Personal Directives Act 2000 RSA c P-6, Advance Health Care Directives Act 1995SNL c A-4.1, Personal Directives Act 2005 SNWT c 16, Personal Directives Act 2008SNSc 8, Consent to Treatment and Health Care

contrary. Thus, the two presumptions operating in the laws preclude the need to have positive proof of mental capacity at the first instance, unless there is reason to doubt the person's mental capacity. Additionally, a majority of the laws in the provinces and territories do not expressly require individuals to be informed when making ADs[266] a position which is similar to the UK.

3.4.3 Applicability of Advance Directives: Scope, Clarity and Subsequent Changes

The laws addressed the mechanisms for which an AD implemented or revoked, consistent with subsequent changes that impact the person's life. For example, if a doctor in British Columbia reasonably believes that the AD's instructions fall outside the scope of the current decision or if the terms are vague, then the AD does not apply.[267] However, most of the laws specify where changes in the personal and medical circumstances occur; they render the ADs ineffective so as not to bind the doctors.[268] Events affecting the personal lives of people who have made ADs include death and divorce. Other circumstances that may invalidate the applicability of ADs are the resignation or loss of competence of the agent or where the court makes a declaration of incompetence. Besides the changes in the personal circumstances and medical advancements, people who change their mind and would like to revoke the AD are allowed to do so, either in writing or in any other form.[269] The laws permitting revocation arising from subsequent changes do not differ from the English position.

Directives Act 1988 PEI c C-17.2, the Health Care Directives and Substitute Health Care Decision Makers Act 1997 S c H-0.001, the Health Care Directives Act 1992 CCSM c H27.

[266] Health Care (Consent) and Care Facility (Admission) Act RSBC 1996 c 181, Personal Directives Act 2000 RSA c P-6, Advance Health Care Directives Act 1995SNL c A-4.1, Personal Directives Act 2005 SNWT c 16, Personal Directives Act 2008SNSc 8, Consent to Treatment and Health Care Directives Act 1988 PEI c C-17.2, the Health Care Directives and Substitute Health Care Decision Makers Act 1997 S c H-0.001, the Health Care Directives Act 1992 CCSM c H27; Health Care Consent Act 1996 SO c2; An Act respecting end-of-life care Bill 2014 (52) c 2 (Quebec)—the law goes further in presuming that at the time the AD is made the person is presumed to be already in possession of information).

[267] Health Care (Consent) and Care Facility (Admission) Act 1996 s 19.8(1).

[268] Personal Directives Act 2000 RSA c P-6, Advance Health Care Directives Act 1995SNL c A-4.1, Personal Directives Act 2008SNSc 8, the Health Care Directives and Substitute Health Care Decision Makers Act 1997 S c H-0.001, the Health Care Directives Act 1992 CCSM c H27; (for BC, if medical advancements occur and the AD expressly provides that the AD still applies regardless of the changes, then the AD is not inapplicable on this basis: s 19.8(2) Health Care (Consent) and Care Facility (Admission) Act RSBC 1996 c 181.

[269] Health Care (Consent) and Care Facility (Admission) Act RSBC 1996 c 181; Personal Directives Act 2000 RSA c P-6, Advance Health Care Directives Act 1995SNL c A-4.1, Personal Directives Act 2008SNSc 8, the Health Care Directives and Substitute Health Care Decision Makers Act 1997 S c H-0.001, the Health Care Directives Act 1992 CCSM c H27; Consent to Treatment and Health Care Directives Act 1988 PEI c C-17.2, An Act respecting end-of-life care Bill 2014 (52) c 2 (Quebec), Personal Directives Act 2005 SNWT c 16.

A classic case concerning ADs in Canada is *Malette v Shulman*[270] where the AD is questioned at the time it is sought to be implemented. Mrs Malette was involved in a car accident, which killed her husband and left her seriously injured. Dr Shulman, the doctor on duty at the emergency department where she was admitted treated her in accordance with the standard medical procedure. At about the same time the nurse found her no-blood transfusion card and alerted Dr Shulman of the same. When Mrs Malette continued to deteriorate Dr Shulman gave her a blood transfusion to save her life.

Three hours after the transfusion, Mrs Malette's daughter, Celine arrived at the hospital together with her husband and a local Church Elder. Celine was adamant that her mother should not have been transfused, confirming Mrs Malette's faith as a Jehovah's Witness. Dr Shulman informed her that Mrs Malette would have died without the transfusion, but Celine maintained her opposition. When Mrs Malette recovered from the transfusion, she sued Dr Shulman successfully for battery and was awarded $20,000 in general damages.

During the course of the trial, evidence appeared that Dr Shulman refused to follow the instructions because "he believed it his professional responsibility, as the doctor in charge, to ensure that his patient received the transfusions".[271] Additionally, he doubted the card as representing her present wishes, because he was uncertain whether Mrs Malette had changed her faith prior to the accident, or that she signed the card due to family pressure, or whether she was fully informed of the risks of refusing blood. In addition, he entertained the possibility that Mrs Malette might have changed her mind had she been conscious and made aware of any medical advice, that she would not have refused blood transfusion at all cost.

The trial court did not find Dr Shulman liable for medical negligence in treating Mrs Malette but liable for transfusing her against her advance refusal thereby violating her rights "over her own body".[272] The trial court applied the presumption of effectiveness to Mrs Malette's AD, for which "no basis in evidence to indicate that the card may not represent the current intention and instruction of the card holder".[273] However, the trial court disagreed with Dr Shulman on the question of informed refusal. According to the trial court, the right to refuse treatment is independent of understanding the risks of refusing treatment. More importantly, the trial court held that just because the AD could not be verified under the circumstances, it did not permit Dr Shulman to ignore the refusal.[274] In other words, the AD had validly limited Dr Shulman's "right to treat".[275]

The Ontario Court of Appeal affirmed the High Court's decision to award damages against Dr Shulman for transfusing Mrs Malette, a Jehovah's Witness against her wishes. Robins JA hypothesised that even if Dr Shulman had the opportunity to

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[270] *Malette v Shulman* (1990) 72 OR (2d) 417.

[271] Ibid, at [7].

[272] Ibid, at [13].

[273] Ibid.

[274] Ibid, at [14].

[275] Ibid.

persuade Mrs Malette to accept a blood transfusion, he was still obliged to follow her AD despite her ignoring his advice or reluctant to consider the matter.[276] The patient was entitled to reject blood transfusion on the basis of self determination and individual autonomy.[277] The Court thus concluded that Mrs Malette had exercised her autonomy through her AD, the only way of notifying others what her wishes were, and accordingly should have been respected.[278] Her right to refuse blood transfusion, as an expression of her autonomy outweighed the state's interest in protecting life and protecting doctor's medical integrity.[279]

In respect of Celine's role in her mother's refusal, the court positioned her as nothing more than confirming her mother's wishes.[280] It is thus not a question of substituting Mrs Malette's wishes for that of Celine's. Mrs Malette's AD was upheld in Canada mostly by virtue of the Charter of Rights which expressly protected her right to religious freedom, which then translated into her right to refuse treatment grounded in her religious freedom.

There are several points arising from the case above. It showcased the prominence of autonomy in the Canadian legal framework. The right to refuse treatment was interpreted from the Charter of Rights which guaranteed the fundamental freedoms of the citizens, one of which is the protection of individual liberty. The Court construed Mrs Malette's right against this autonomy protecting framework, upholding her refusal to receive blood transfusion at the peril of death. In addition, her right to life, security and liberty is guaranteed under s 7 of the Charter of Rights. The importance of autonomy is accentuated in the role AD played in this case. The Court took the position that an AD is presumed to be valid until proven otherwise. Naturally, in order for this presumption to be effective, it is necessary that the ingredients constituting or giving effect to this presumption are presumed to be effective too, for example the presumption of mental capacity. A person is presumed to have the mental capacity unless proven to the contrary. The Court had given effect to this presumption to Mrs Malette. The statutory regimes concerning ADs in Canada have incorporated the presumption of effectiveness to ADs. Another point arising from this decision is that an AD refusing treatment need not be informed. Up until this point, there are still divergent views about whether refusals need to be informed or otherwise. Mrs Malette's case indicated that a refusal need not be informed.

Mrs Malette's case would likely have a different outcome under the MCA, in terms of doubts arose about her mental capacity, voluntariness, understanding of her refusal and continued applicability of her AD. Moreover, as it was a life-saving blood transfusion that she refused, it would fall under an AD refusing life sustaining treatment. As such, the AD had to be written, signed and witnessed. Her no-blood transfusion card was in a written form and signed but not witnessed. Even though the presumption of mental capacity applies, compliance to the form is essential.

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[276] Ibid, at [25].

[277] Ibid, at [25], [41].

[278] Ibid, at [32].

[279] Ibid, at [35], [37].

[280] Ibid, at [46].

Assuming at the very least that it did not fall under the life sustaining treatment category and was merely an advance decision refusing treatment, there would still be doubts about the validity of her AD. As regards Celine's role as her daughter in confirming her mother's wishes, it would be unlikely that her views would be accorded any larger weight other than merely confirmatory of her mother's wishes. The concept of substituted judgment is not applicable in the common law jurisdiction. Dr Shulman would not be liable under ss 25(1) and 26(2) of the MCA for transfusing her unless her AD was valid and applicable to the situation.

3.4.3.1 Formal Requirements

Similar to its English counterpart, the Canadian territories and provinces have specific formal requirements for making ADs.[281] All the states or territories with statutory regime require ADs to be written, dated and signed. Despite the requirements for written, signed and witnessed ADs, the failure to use the statutory forms will not invalidate the ADs.[282] The writing requirement precludes the uncertainties about whether an AD exists while the date can illuminate how long ago it was made, although this does not necessarily indicate that the AD is genuinely made. This is because people can forget to review it after a while and the AD does not reveal their state of mind when it was written. It is only one more clue towards putting the picture together of what happens at the time the person makes the AD. The flexibility to depart from using the statutory form prevents slavish adherence to forms over substance.

3.4.3.2 Doctors' Liability

Some states in Canada specify circumstances where doctors are permitted to disregard ADs. When it comes to applying the AD, most of the laws do not grant discretionary powers to the doctors to depart from complying with the AD.[283] This flexibility suggests that the laws acknowledge the special characteristics and realities of AD—that it is not always known whether an AD exists or not or whether it has been revoked and becomes inapplicable. A doctor who is unaware of an AD does not attract any liability. Doctors are protected when they acted in reliance of the AD, similar to the English position. If a doctor relied upon the AD in good faith, or acted contrary to the AD there is no liability on the doctor.[284] When a

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[281] Except for Nunavut, Yukon where the common law is still applicable in the absence of statutory regime.

[282] Saskatchewan and the Northwest Territories however explicitly invalid ADs that are not written, dated and signed.

[283] Except for PE law where if compliance with the AD is contrary to the doctor's ethical standard, the doctors are permitted to disregard the AD: s 30(1)(b) Consent to Treatment and Health Care Directives Act 1988, the Saskatchewan law similarly permits doctors not to comply with the ADs if it is contrary to the doctor's ethical standards.

[284] Consent to Treatment and Health Care Directives Act 1988 PEI c C-17.2, s 30(1).

doctor contravenes an AD, it is because the doctor is not aware of its existence or if complying will not be "realistically possible" or "contrary to the ethical standards of his or her profession".[285] Doctors under the Prince Edward Island law are required to reasonably inquire if patients have ADs but it does not appear that the failure to inquire will incur liability. Likewise, doctors in British Columbia are not required to inquire beyond reasonable effort as to whether an AD exists. This means that where it is reasonably possible, doctors should inquire but nothing more. This illustrates some variance as regards ascertaining the ADs' existence. It is unknown why the MCA did not make explicit reference to this inquiry. Inquiring the existence of an AD could possibly be best practice. This could occur in both emergency and non-urgent situations, although in urgent situations, it may not be feasible to inquire.

3.4.4 Conclusion

It is evident that the legislators framed the ADs laws on the basis of protecting and promoting the primacy of autonomy, as demonstrated in the laws of the majority of provinces and territories,[286] and closely linked to the protection of the citizen's fundamental rights and liberties as entrenched in the Charter of Rights. ADs, or personal directives, are thus viewed as tools to exercise such autonomy.[287] The uncertainties regarding the withdrawal and withholding of treatment prompted the Parliament to legislate laws in order to clarify the position—both in the rights of individuals to make decisions and the other to clarify what doctors should do in the face of such refusals and what are their legal position.[288] While the laws respect the autonomy principle[289] they also give due consideration to the doctors' ethics for they have their

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[285] Ibid, s 30(1)(b).

[286] Health Care Directives Act 1992 CCSM c H27; Health Care (Consent) and Care Facility (Admission) Act RSBC 1996 c 181; Personal Directives Act 2000 RSA c P-6, Advance Health Care Directives Act 1995SNL c A-4.1, Personal Directives Act 2008 SNSc 8, Health Care Consent Act 1996 SO c2.

[287] Health Care Consent Act 1996 SO c2; Personal Directives Act 2000 RSA c P-6.

[288] For example, Manitoba Law Reform Commission, Report in Self Determination in Health Care (Living Wills and Health Care Proxies), June 1991, Report #74; in respect of Newfoundland and Labrador debating An Act Respecting Advance Health Care Directives And The Appointment Of Substitute Health Care Decision Makers." (Bill No. 1), where the Minister of Justice Mr. Robertsstated that: "The main principle for the enactment of the law is: protection of liberty under the Canadian Charter, self determination, protection of liability of the healthcare professionals, the need for educating the public." Similarly in Alberta (Personal Directives Act Bill 35, April 22, 1996) at 1272–1273; (May 9, 1996) at 1762–1763; (May 22, 1996) at 2061; Northwest Territories Personal Directives Bill 7 (Legislative Assembly 4th Session Day 1, 15th Assembly, May 25, 2005) at 90–91; (May 30, 2005); Saskatchewan Health Care Directives and Substitute Health Care Decision Makers Bill 66 (May 16, 1997) at 1757–1758; PEI Consent to Treatment and Health Care Directives Act, Bill 40 (Legislative Assembly 20 Apr 1996) at 944.

[289] For example, the Alberta Parliamentary debates when debating the Personal Directives Act 2000, Manitoba Law Reform Commission, Report in Self Determination in Health Care (Living Wills and Health Care Proxies) (June 1991) Report #74.

professional ethics and duties to adhere to. While the laws do not specify what circumstances are those, this will most likely include conscientious objections, which permits doctors to refer the patient to another doctor. Autonomy is conceived in the sense of empowering the person in making the AD.[290]

Although the Canadian statutory regime installs formal requirements to make ADs, it includes the presumption of the effectiveness of a valid AD and is less adamant in requiring individuals to use statutory forms to make ADs. The requirement for mental capacity is standard, as with the English position, they require an understanding to make the ADs. This suggests an effect that is least restrictive to the use of ADs; which is unsurprising given its constitutional framework that amplified the individual liberty and consequently the right to refuse treatment through ADs. Although the decision of Mrs Malette can be confined to its facts, it is reasonable to assume that ADs can be valid and legally binding. The laws generally provide presumptions that underlie the validity of ADs. The standards are no different from a contemporaneous refusal of treatment.

In respect of compensation, this is still a controversial issue. There were cases in the United States where the courts have refused to award damages for patients whose lives were saved by doctors who continued treatment because of uncertainty in the validity of ADs or whether any ADs existed.[291] The common law approach is likely to follow the existing trend in the US. Therefore the *Malette v Shulman* case should be construed as limited to its facts in terms of the award of compensation for contravening a patient's refusal to consent to treatment. So far there have been no cases in Canada that illustrate this trend and that it is likely that courts will be slow to award damages to the patient whose life has been saved despite treating contrary to the terms of an AD. It is unlikely then that there will be a drastic change in the current system.

3.5 Case Study IV: Singapore

3.5.1 Overview of ADs in Clinical Practice and Society

Singapore is a culturally distinct landscape compared to the three western jurisdictions examined earlier. Issues of death are rarely broached amongst family members for fear of being accused as acting unfilially to the elderly. Every person in paid employment is mandated to contribute into a personal Medical Savings Account, which forms part of the person's estate upon death and the dependents are paid for

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[290] Health Care (Consent) and Care Facility (Admission) Act RSBC 1996 c 181; Personal Directives Act 2000 RSA c P-6, Personal Directives Act 2008 SNSc 8.

[291] For example, *Anderson v St Francis-St George Hosp Inc* 671 NE 2d 225, 227 (Ohio 1996); *Bartling v Glendale Adventist Medical Center* 194 Cal App 3d 961 (1986); *Grace Plaza of Great Neck Inc v Elbaum* 183 AD 2d 10 (NY Sup Ct App Div 1992).

through this account.[292] Parents who are dependents can rely on this funding, consistent with filial piety towards parents and the elderly.[293] This structure contributes to the existing environment where medical decision-making is rarely patient-centred and notions of autonomy as understood in the western democracies are almost non-existent. This background is pertinent as it provides a context to the reason for the approach adopted in its Advance Medical Directives Act 1996.

The blend of socio-cultural influences shaped a unique medico-legal culture in Singapore. The predominantly Chinese population meant that Confucian values permeated their lives, including the "value of life, the obligation to do one's best to rescue the dying" resulting in an acceptance of paternalistic practices.[294] The attitude towards decision-making in healthcare reflects that familial involvement is still very significant. A study on the doctors' attitude revealed that "many doctors are prepared to involve family members in making a consensus decision-making" when patients refuse treatment.[295] Although Singapore doctors are generally supportive of the AD concept, they were not unanimous about legislating ADs.[296] The doctors interviewed in the survey who were not supportive of ADs felt that they were in the best position to decide for their patients.[297] Doctors cited fear of endorsing euthanasia as the main reason for their objection to legislation on ADs.[298] A study aimed at discovering factors that significantly influence end-of-life decision-making among a small sample of Singaporean healthcare professionals revealed that doctors and nurses generally prioritise patients' wishes and beliefs over family wishes in the event of conflict when making such decisions, showing signs of prioritising patient autonomy.[299] However, the patients' ADs were ignored when the patients became incompetent and family wishes prevailed, probably attributed to the importance of familial role in medical decision making.[300]

The Singapore Medical Council Ethical Code and Ethical Guidelines 2002 reveal a consistent approach towards treatment of patients which favours best interests of the patient over autonomy. In fact the word autonomy does not even exist in the code. A pioneering study in Singapore investigating doctors' perceptions about care at the end of life revealed several essential points.[301] It appears that religious beliefs

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[292] Ibid, at 156, 157.

[293] Ibid; Chan TE, Peart NS and Chin J "Evolving legal responses to dependence on families in New Zealand and Singapore healthcare" (2014) 40 J Med Ethics 861 at 863.

[294] Ibid, at 59.

[295] David Chan and Lee Gan Goh "The Doctor-Patient Relationship: A Survey of Attitudes and Practices of Doctors in Singapore" (2000) 14(1) Bioethics 58.

[296] KH Tee, LT Seet, WC Tan, HW Choo "Advance Directives: A Study on the Knowledge and Attitudes among General Practitioners in Singapore" (1997) 38(4) Singapore Med J 145 at 145.

[297] Ibid.

[298] Ibid, at 147, 148.

[299] Wei Ting Foo and others "Factors Considered in End-of-Life Care Decision Making by Health Care Professionals" (2013) 30 Am J Hosp Palliat Care 354.

[300] Ibid, at 357.

[301] Jacinta OA Tan and Jacqueline JL Chin with contributions from Terry SH Kaan and Tracey E Chan "What doctors say about care of the dying" (The Lien Foundation, Singapore, 2011).

influence end-of-life care in the ethnic Chinese population, thereby overlooking the necessity and potential benefits of ADs.[302] In addition, Singaporean families felt challenged to broach ACP concerning terminal care or will writing with their relatives for fear of being accused of "wishing them dead or wanting their property."[303] Some Singaporean doctors were neither aware of the Mental Capacity Act 2008 nor its relevance to end-of-life decision-making, while those who knew about it felt that in practice there was not much difference in terms of decision-making for patients who were competent or incompetent because families were very much involved in medical decision-making.[304] Doctors also highlighted the issue of stability of preferences for ADs among patients due to various factors, such as individuals who make ADs while they are depressed or out of consideration for others' interests and that they are liable to change their minds at a later stage.[305] Another point raised by doctors was that patients were under the misconception that they will receive less treatment or have treatment withheld from them if they have ADs should they change their minds later but had become incompetent to revoke their previous wishes.[306] This shows the differences between the doctors' perspectives and the patient's perspective.

3.5.2 Legal Framework Governing ADs in Singapore

Singapore has a unique legal landscape, in that it inherited the English common law, but with modifications to accommodate the societal and cultural needs in an Asian setting.[307] In respect of laws governing death, the law consists of the Penal Code, common law, and the Mental Capacity Act 2008 which came into force in 2010. The 2008 Act provides generally for substitute decision-making, modelled heavily on the English MCA 2005 but excluding the provisions on ADs. ADs are separately regulated in the Advance Medical Directive Act 1996 ("AMDA").[308] Singapore's Mental Capacity Act and AMDA govern different aspects of end-of-life care. The AMDA deals with refusal of life-saving or life sustaining treatment specifically while the Mental Capacity Act deals with a wide range of incapacities, such as the appointment of attorneys for financial matters and medical matters other than life sustaining treatment. The AMDA is the focus because it is the principal statute governing ADs in Singapore. References to the definitions or tests of mental capacity, where applicable, will be made to the Mental Capacity Act 2008, as the AMDA neither defines nor provides the test for mental capacity or mentally disordered means.

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[302] Ibid, at 6.

[303] Ibid, at 9.

[304] Ibid, at 37.

[305] Ibid, at 42.

[306] Ibid.

[307] Chan TE, Peart NS and Chin J "Evolving legal responses to dependence on families in New Zealand and Singapore healthcare" (2014) 40 J Med Ethics 861 at 863.

[308] Revised 1997.

The impetus for legalising ADs arose against the background of increasing awareness by Singaporeans of averring their rights through medical negligence or malpractice suits against doctors, which in turn created a sense of anxiety within the healthcare professionals regarding their legal position in respect of ADs.[309] While the legislative reasons may be focused on the need for clarifying the law, or asserting the autonomy principle in other jurisdictions surveyed thus far, an aspect peculiar to Singapore in respect of ADs is the consideration given to the multi-religious views of various segments of the society.

3.5.2.1 Validity of Advance Directives: Capacity, Voluntariness and Understanding

The MCA defines mental capacity in exactly the same way as the English MCA.[310] However, it differs from the English and Canadian approaches in respect of the presumption of mental capacity because a witness (a doctor) has to "ensure that the patient is not mentally disordered."[311] The absence of the presumption of mental capacity, together with the requirement for the witness to take reasonable steps to ensure that patients are informed about the nature and consequences of making the AD, suggest that doctors are required to have positive proof of mental capacity as a pre-requisite to make an AD under the law.

3.5.2.2 Application: Scope, Clarity and Subsequent Changes

ADs are known as advance medical directives under the AMDA. It has a very narrow scope which impacts its application, where it can only be used to prevent extraordinary life sustaining treatment to a terminally ill person whose death is imminent.[312] Their purpose is therefore to avoid prolonging the dying process.[313] If the person is suffering from a terminal illness and only requires routine treatment to sustain life, the AD is inapplicable. Thus, terminal illness is the cornerstone of the AMDA; unless and until the person is satisfactorily certified by a panel of specialists unanimously to be terminally ill and in need of extraordinary life sustaining treatment, the AD is inapplicable.

Terminal illness within the language of the AMDA refers to an incurable condition with no reasonable prospect of recovery, where death is imminent and extraordinary life sustaining treatment would be futile.[314] This requirement connotes a medical

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[309] Select Committee on the AMD Bill *Report of the Select Committee on the Advance Medical Directive Bill (Bill no. 40/95)* (Singapore Parliament, Govt Printers, 1996).

[310] Mental Capacity Act 2008 (SG), s 4.

[311] AMDA 1996 (SG), s 4.

[312] AMDA 1996 (SG), s 3(1).

[313] Preamble to the AMDA 1996.

[314] Ibid, s 2.

judgment. Extraordinary life sustaining treatment however in the law excludes palliative care, where treatment is still given to reduce pain, suffering, discomfort and food and water. The significance of a finding in terminal illness is such that s 8 expressly refers to the necessity of appointing a panel of experienced specialists for the purpose of diagnosing what constitutes terminal illness. There is no such feature or restriction in the other jurisdictions. Reading the provisions collectively points to the conclusion that an AD refusing extraordinary life sustaining treatment will be applicable to a person who is dying. In this sense the law is very restrictive in respect of binding ADs, compared to Canada and England and Wales. The English MCA permits creating ADs which is not necessarily restricted to terminal illness only.

An AD can only be implemented after satisfying the formalities. So far there seems to be a lack of cases that directly deal with how an AD under the AMDA is applied and implemented. The closest is *Re LP (adult patient: medical treatment)*.[315] It was an urgent application brought by the hospital seeking the Court's declaration that it would be lawful for the hospital to amputate both her legs in her best interest.[316] Ms LP had been diagnosed as diabetic and had sought medical advice when she felt pain in her legs. Her doctors informed her that an amputation was necessary, but she refused to consent to the surgery. She wanted the doctors to save her legs "at all costs."[317] She was, however persuaded to amputate her right toe. Despite that her condition had worsened and once again she insisted that doctors should not amputate her legs. Although the danger of death was not apparent at that time,[318] she then fell into a septic shock and became comatose. She had not been made aware that without surgery she would die. Her attending doctor, together with four other medical specialists were unanimous that the operation would be in her best interests, her request to the doctors to save her legs at all cost confounded them.[319]

The Court granted the doctor's application on the basis of LP's best interest despite her prior refusal.[320] In explaining best interest, the court concluded that doctors' consideration of what forms a patient's best interest is a professional medical judgment, which differs from a patient's perspective.[321] The Court viewed LP's prior request not to amputate as most likely "made without the benefit of medical advice of impending death."[322] Based on the evidence, the Court could not find conclusively that LP "had clearly and expressly refused her consent to the surgical operation" "knowing that it was the only treatment to save her from impending death."[323] As such, her best interest from the medical point of view dictates that she should undergo amputation.

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[315] *Re LP (adult patient: medical treatment)* [2006] 2 SLR 13; [2006] SGHC 13.

[316] Ibid, at [1].

[317] Ibid, at [2].

[318] Ibid.

[319] Ibid, at [3].

[320] Ibid, at [3].

[321] Ibid, at [9].

[322] Ibid, at [11].

[323] Ibid.

The Court also remarked that the US concept of “living wills” differed from the advance medical directive applicable in Singapore in terms of the scope, nature and procedure.[324] In addressing the question of substituted judgment, the Court appeared to refer to LP’s prior contemporaneous refusal as not a refusal on its own but rather a piece of evidence that could be potentially important if the substituted judgment approach is adopted.[325] This position would be unlike that of Mr C considered earlier in England whose contemporaneous refusal that was intended to become a legally binding AD in the future was upheld.

It is evident from the language of the AMDA and the court that doctors play a prominent role in medical decision-making. Medical judgment is a prerequisite for withdrawing treatment. Families do not acquire any status under the law, in stark contrast to the bedside reality where family-doctor collusion occurs frequently. This is not to say that there is absolutely no doctor-family collusion in the previous three jurisdictions. However the Singaporean societal make up and various ethnic populations professing different religious beliefs made it a more pronounced feature compared to the western democracies.[326] In view of the restrictive scope, it is likely that there is little room for subsequent changes to occur. However, the law does provide for revocation of ADs which must be witnessed, but can be made orally or in writing and registered where reasonably possible.[327]

3.5.2.3 Formal Requirements

The formalities governing ADs under the AMDA are very stringent, with particular emphasis on specific step-by-step approach. An AD has to be in prescribed form in order to be valid with the requirements to sign, date and witness the AD.[328] The witness is not just as to the signature but also to certify (if the person who is a witness is a doctor) that the person who is making the AD is not mentally disordered. This is in contrast to the English Mental Capacity Code of Practice which clarified the purpose of witnessing in s 25(6) in respect of ADs refusing life sustaining treatment. After satisfying these requirements, the AD must be registered (s 5) as a sign of acknowledging the receipt of the AD. This process is important because it impacts upon the actionability and implementation of the AD. The law provides that an AD that is not registered cannot be acted upon.[329] This feature is absent in England and Wales and Canada. The failure to register the AD is fatal to the application process. Registration also enables anyone who is aware of the AD to object.[330]

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[324] Ibid, at [8].

[325] Ibid.

[326] James A Low and others “Reducing Collusion between Family Members and Clinicians of Patients Referred to the Palliative Care Team” (2009) 13(4) The Permanente Journal 11.

[327] Section 7 AMDA.

[328] AMDA 1996 (SG), ss 3, 4.

[329] Ibid, s 5(3).

[330] Ibid, s 6.

Confidentiality is protected; it would be highly unlikely for anyone other than the attending doctor who would know about the existence of the ADs. The AMDA required doctors to ascertain that the AD has been registered, that the patient has been certified as terminally ill and whether the patient is pregnant prior to acting on an AD.[331] This is to ensure that the AD had complied with the legalities of AMDA prior to implementation.

3.5.2.4 Doctors' Liability

The prohibition to enquire about ADs stands in contrast to the Canadian approach and other jurisdiction which does not expressly prohibit a doctor from enquiring about it.[332] The law's highly restrictive and cautious approach suggests a discouraging approach towards making ADs. Patients such as *Mr C, Miss T, Mr All Means All* and *Miss AE* would have no chance at all to even consider making an AD under the AMDA. They could express their preferences but those preferences will not legally bind any healthcare professionals. The doctors have to decide and certify whether the patient is actually terminally ill, subject to further confirmations from other specialists, who must come to a unanimous decision,[333] an approach which is very much doctor-centred rather than preferring patient autonomy.

3.5.3 Conclusion

The highly restrictive approach to ADs in Singapore can be understood in the context of its socio-medical landscape at the time and the cultural and societal background. As explored above, the combination of these influences permit a situation where doctors play a significant medical authority, fuelled by a strong family-oriented structure made personal decision-making harder to achieve. The medico-legal landscape has translated this attitude into its laws. It was intended to give legal effect to ADs specifically for refusing artificial prolongation of life. The National Medical Ethics Committee recommended legislating ADs after extensive consultations with various religious and professional bodies.[334] The Select Committee received submissions expressing a range of concerns, from the potential conflict between ADs and Asian family values to impact upon patient-doctor relationship and permitting euthanasia.[335] These concerns were duly noted and the current AMDA provisions reflected

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[331] Ibid, s 10(3).

[332] This is provided for in ss 15(1) and (2) AMDA.

[333] Section 9 AMDA.

[334] Ibid.

[335] Ibid.

the safeguards installed and specific procedural processes that need to be followed before an AD can operate.[336]

AD is only permitted in exceptionally limited and specific circumstances; otherwise they are not legally binding on the doctors. Healthy individuals contemplating making ADs may find it unduly cumbersome and they cannot elect to refuse treatments such as resuscitations in advance, or blood transfusions. It is very likely that Jehovah's Witnesses may be unable to use ADs under the law to refuse blood transfusion in routine surgical procedures or in the event of emergencies. However, there may be separate considerations when the matter arises out of respect for their faiths but at present, ADs conceived under the law are only applicable for people who are certified to be suffering from terminal illness. It is a more specific AD use compared to New Zealand, because the history demonstrated that both come from very different perspectives. The AMDA has also set a higher bar compared to contemporaneous refusals and common law ADs.

It is least reflective of the autonomy concept, either from a non-interference approach or supportive way. The AMDA provisions operate on a benevolent paternalistic basis, reflected by a doctor-centred approach in considering when to withhold or withdraw treatment. There are no measures to support or advise individuals wishing to make ADs. While the Parliament may have the intention of applying the popular notion of autonomy in medical law in Singapore, the societal structure may not yet be ready to embrace this concept. Doctor-family collusion in medical decision-making is rampant, understood in a contemporaneous setting.[337] It is not surprising that even with an AD the patient's wishes are the last to be heard, or not given any voice at all. Only if it coincides with the best medical practice or doctor's opinion on what is best for the patient clinically that those wishes are "respected."

3.6 Common Themes and Divergences

3.6.1 Validity of Advance Directives

An AD will be valid and binding if it is made by a person who is mentally competent, acting voluntarily and understands the nature and consequences of the refusal. These requirements are unanimous across the jurisdictions and similar to the requirements of contemporaneous refusals. There is however some divisions in respect of whether an AD refusing treatment needs to be informed. One of the approaches the courts used in determining whether an AD was valid or otherwise is through ascertaining the patient's mental capacity. A presumption of capacity is a rebuttable presumption and the test for mental capacity is whether the patient at the time of making the AD

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[336] Ter Kah Leng and Susanna Leong Huey Sy "Advance Medical Directives In Singapore" 1997 (5) Med L Rev 63 at 66, 67.

[337] Select Committee on the AMD Bill *Report of the Select Committee on the Advance Medical Directive Bill (Bill no. 40/95)* (Singapore Parliament, Govt Printers, 1996).

has understood the nature and consequences of the refusal. In a majority of cases, the courts relied upon a doctor's assessment of a patient's mental capacity. As the common law cases demonstrated, cases where doctors have had the opportunity to assess the patients or where the courts had the chance to observe their demeanours during proceedings improve the chances of the ADs being accepted and confirmed as valid. Once the patient becomes unconscious, it is impossible to verify the instructions in the AD and no accurate retrospective assessments can be made.

3.6.2 Application

Having established the existence and validity of an AD, the next step is applying the AD. Is the AD clear and applicable to the circumstances that have arisen? This can refer to the type of treatment that a person can refuse in an AD. Most of the cases deal with refusing blood transfusions, with some specific towards leg amputation and feeding. Most of the applications were urgent and all refusals are at the risk of death. A question then arises as to whether the terms are clear enough to exclude the interest in protecting life. The courts, when faced with applications to ascertain the validity of ADs enquire into the surrounding circumstances when the AD was made. This naturally turns to the person's mental capacity, voluntariness and understanding of the nature and consequences of the refusal. The presumption of mental capacity, both under the common law and the statutes addressed this concern. Whether these common law cases bear out this presumption remains to be seen. As demonstrated from the discussions above, where the AD risks death, the person's mental capacity will be challenged. Canada's approach goes further than other jurisdictions in installing the presumption of effectiveness of the AD, where ADs are presumed to be valid until proven to the contrary. Naturally this includes the presumption of mental capacity.

3.6.3 Subsequent Changes

An important factor to consider when an AD is implemented is whether any changes have occurred since the AD is made. This relates to a change of mind or the change of personal circumstances affecting the applicability of AD. The common law case *AK* highlighted the necessity to review whether the decision still represents the person's wishes. The longer the gap, the more liable it is to suspicion of possible changes occurring. The courts thus far did not set any specific time limit. All the jurisdictions addressed the issue of subsequent changes in the statutory regime, including changes in the personal circumstances, medical advancements and change of minds. In this respect, Canada approached the changes in a more specific way by providing for specific events that would revoke the ADs automatically, such as death or divorce. In Singapore, the window for changes to occur is almost zero.

In jurisdictions with statutory regimes, in addition to the requirements of mental capacity, voluntariness and understanding of the refusal, some mandate the use of specified forms as the requirement for validity. While an AD can be made verbally or in writing under the common law, all the jurisdictions require that an AD be written, or to reduce verbal ADs into written forms. Thus, two additions to the common law as introduced by statutes are the use of AD forms and the formalities of written, signed, witnessed and dated ADs. The English approach requires only ADs refusing life sustaining treatment conform to the written, signed and witnessed requirement while Canada adopted these formalities for all types of ADs. Singapore goes further by requiring ADs to be completed in a prescribed form and registered in order to be valid and binding. There is also mutual recognition of ADs created in different provinces and territories, supporting the idea that a patient's prior expressed preference prevails over form.

3.6.4 Doctors' Liability

The common law cases examined thus far did not reveal much about a doctor's liability when they give effect to a patient's AD. The statutes across the jurisdictions however addressed this concern by expressly protecting doctors from liability when they acted according to the patient's AD. In respect of liability on doctors Mrs Malette's case was notable for the compensation given to her when Dr Shulman disregarded her no-blood transfusion AD.

3.7 Conclusion

The judicial disputes reflect several concerns highlighted in the previous chapter. In the AD debate I highlighted the justifications for and arguments against ADs which are broadly categorised into two. ADs are justified on the principle of autonomy, and that since the law recognises the right to refuse treatment, this right can be extended to govern a refusal which is intended to operate in the future. The opponents of ADs take issue with their inherent flaws, citing that it harms the person's current interest and that it is impractical to apply. This book is premised upon the basis that ADs are a valid tool for medical decision-making, and the law and courts have recognised this right. The second challenge is the one that is mostly relevant to the courts, particularly; it deals with the decision-making process in ADs. The courts have upheld ADs when the evidence is clear that the AD represented the autonomous wishes of the person because it has been validly made. The mechanisms in ascertaining ADs are the same as the one used in ascertaining a refusal of treatment made contemporaneously.

Laws adopted in the jurisdictions examined so far restrict the use of AD through the scope of refusal permitted and the power of doctors to depart from the terms of the ADs. Some laws stipulate which ADs are binding on doctors and which statements are merely advisory. The laws generally aim to clarify the legal position of doctors who adhere to the ADs and protect them from civil or criminal liability or both for acting upon or against the patients' ADs. Incorporating these provisions within the laws provide 'safety nets' to doctors and some assurances that they would not be liable if they abide by the ADs or ignore the ADs on reasonable grounds that the ADs no longer apply.

The theoretical framework underpinning ADs in the laws is autonomy. The English approach, as evidenced by the MCA is best said to be based on a best interest principle, although autonomy is acknowledged in specific matters. The Canadian approach reflected a stronger autonomy-inclined regime, where decision-making occurs in a three-tiered manner, firstly autonomy, followed by substitute decision-makers (chosen by the person) and then finally best medical interest. The role of autonomy is more reflected in their statutes where there exist supportive provisions. While it permits the appointment of substitute decision-makers, their powers are only exercisable to the extent that they are agreed to by the maker of the AD. This brings the involvement of families or whomever the person wishes to designate to in medical decision-making. The Singapore approach is underpinned by a best interest approach and sanctity of life concept based on adherence to religious beliefs and family relations. Hence, autonomy is not a primary rule underpinning the law. Additionally, the cases and laws have thus far been cautious in upholding legally binding ADs and emphasised the decision-making on the patient and the role of doctors; but have not accorded specific roles for family members in the process, other than as substitute decision-makers.

The conception of autonomy differs across each jurisdiction. New Zealand conceptualises autonomy as a right and this right then translates into the reciprocal obligation to provide support necessary to effectuate that right. In order to facilitate this right to exercise autonomy, various support measures are instituted to achieve those rights. In stark contrast, Singapore constructs autonomy in a highly regulated manner. It is under very specific situation that the right can be exercised, and this can be perceived as a very weak notion of autonomy. It would not be too much to say that it is paternalism in action when it comes to AD. Canada sits in the middle of this spectrum. It recognises the significance of autonomy and strives to achieve those rights. It is very likely that New Zealand will sit closer to Canada within the spectrum, given its medico-legal history and the rights contained in the Code of Rights. The divergent responses towards ADs are also attributed to the legal background operating in various legal systems. The English courts are more likely to err to the side of preserving life in their approach towards ADs. While the English law permits the use of ADs, only certain ADs are treated as legally binding. Singapore is an example where the use of AD is highly restrictive. Despite the differences, they share the same recognition that AD is useful, but the extent to which they are viewed as binding varies.

Chapter 4
Rethinking the Approach to Advance Directives

4.1 Introduction

The challenges in implementing advance directives called for an understanding of the distinctions between advance decision-making and contemporaneous decision-making. It is clear from the cases that where there is the opportunity to verify the decision-making process, the AD is more likely to be accepted as valid and applicable. Consequently, this warrants an alternative approach in the form of supported decision-making to ADs.

An advance directive is premised upon the principle of autonomy, which occupies a pre-eminent position in medical law. A contemporaneous refusal of life-saving or life-sustaining treatment is respected under the common law, even if the consequence of the refusal is death.[1] The following two cases illustrate the qualities of and the courts' approaches towards contemporaneous refusals.

Re B concerns a 41-year-old tetraplegic woman's wish to remove the ventilator that was keeping her alive. The dispute came about because Ms B claimed that, while she was mentally competent to refuse ventilation, she had been treated against her will by the hospital. B was diagnosed as suffering from an intramedullary cervical spine cavernoma, which is a malformation of the spinal cord,[2] resulting in her becoming completely paralysed from the neck down. She came under the care of the hospital at its Intensive Care Unit, and was ventilated when she began having respiratory problems. However, she refused to be continually ventilated, and informed the consultant anaesthetists about her previous living will authorising treatment withdrawal

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[1] *Re B (adult: refusal of medical treatment)* [2002] EWHC 429 (Fam); *St George's Healthcare NHS Trust v S* [1998] 3 WLR 936 (CA).

[2] It is a rare disease which can be fatal, afflicting more women than men with symptoms that are not easily diagnosed: See-Sebastian, H Ester and Robert E Marks "Spinal Cord Intramedullary Cavernoma: A Case Report" (2013) West Virginia Medical Journal at http://www.thefreelibrary.com/Spinal+cord+intramedullary+cavernoma%3A+a+case+report.-a0331687720. Accessed 2 June 2017.

H. Y. Chan, *Advance Directives: Rethinking Regulation, Autonomy & Healthcare Decision-Making*, International Library of Ethics, Law, and the New Medicine 76,
https://doi.org/10.1007/978-3-030-00976-2_4

but was told that the terms were insufficiently clear to warrant ceasing ventilation. After she made this request, she was assessed by an independent consultant psychiatrist and returned to the Intensive Care Unit. Her intention to cease ventilation grew more serious when she formally instructed the hospital to accede to her request through her lawyers. The medical evidence was that there would not be recovery in her condition and withdrawing ventilation would cause B's death.

B applied to the court for a declaration that she had been unlawfully treated at the hospital because the hospital refused to cease ventilation according to her wishes. At issue was her capacity to refuse treatment. Her mental capacity was assessed continuously by several consultant psychiatrists who initially found her to be mentally competent. Preparations to switch off the ventilator were aborted once it became known that the psychiatrists, for unknown reasons, changed their reports. B was treated with anti-depressants. Although B was subsequently reassessed by the psychiatrists and a consultant anaesthetist, they failed to conclusively state whether she possessed mental capacity or not. B then requested to be independently reassessed, this time by a consultant psychiatrist from another hospital who found her to be mentally competent to refuse treatment and was not suffering from depression.

The Court heard evidence from five doctors regarding B's mental capacity. Although four of the doctors were of the opinion that B was mentally competent to refuse treatment, Dr I, an independent consultant psychiatrist with broad experience of patients like Ms B feared that respecting her autonomy would rob her of the chance for potential benefits arising from continued medical support in the future. The Healthcare Trust was not persuaded that B possessed mental capacity on the basis of her previous inconsistencies towards treatment withdrawal and the lack of experience of positive sides of rehabilitation.

The High Court concluded that where a patient possesses the mental capacity to decide, and has been relevantly informed about their medical options, and has decided to refuse the medical treatment offered, B's right to cease treatment prevailed over the medical team's wish to keep her alive. As such, where autonomy and beneficence come into conflict, the right of a competent person to refuse treatment must prevail.[3] Besides the evidence of the doctors and the submissions of the Healthcare Trust, the Court heard Ms B's written and oral evidence, where she had the opportunity to explain to the Court that she had been firm in requesting the removal of the ventilator. In response to the doctors' observations that she was relieved that the ventilator had not been turned off after she was assessed as being incompetent, she explained that the relief was not that she was still being ventilated, but rather, she was relieved at the prospect of avoiding the stress of saying goodbye to her family and friends. Once her mental capacity was established on 8th August, she rejected the rehabilitation option, consistent with her previous view to cease ventilation.

While Ms B's decision to remove the ventilator caused distress to her medical team, her right to refuse treatment was ultimately respected. Best interest considerations are irrelevant where a person is competent. Autonomy's pre-eminence is extended to respecting decisions that could prove catastrophic to a healthy person.

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[3] *Re B (adult: refusal of medical treatment)* [2002] EWHC 429 (Fam) at [27].

This would be true even if everyone else thought she would probably change her mind later if she were to be kept alive.

St *George's Healthcare NHS Trust v S* is an even stronger illustration of autonomy's superiority over beneficence in a contemporaneous refusal setting.[4] This case differed materially from Ms B in that it involved a healthy pregnant woman whose life was at risk. S was 36-week pregnant and diagnosed with severe pre-eclempsia but refused to have her unborn child delivered by C-section despite risking her own life as well as her baby's life. She wanted to have her baby in a barn in Wales and refused any form of intervention. Her adamant refusal led the doctor to have her committed under the 1983 English Mental Health Act ("MHA") for a mental health assessment. While she was in hospital, she continued to refuse consent to treatment.

St George's Healthcare NHS Trust then lodged an ex parte application (without S's knowledge) for an urgent declaratory order authorising the performance of a C-section. Believing the case to be a life and death situation and unaware that S had been found to be competent, Hogg J granted the application. S was anaesthetised against her will and a C-section was performed. Following the safe delivery of a healthy baby girl, S's detention under the MHA was terminated. S was angry about the intervention, firmly adhering to her view that she did not want any medical intervention for the delivery of her baby. She appealed against Hogg J's decision.

The Court of Appeal allowed S's appeal, cementing the principle that a competent person has the right to self-determination even at the risk of her own death and that of her unborn child. S's decision was entitled respect despite holding views that are not widely regarded as rational. Despite having a history of mental illness, S was found to be competent and understood the nature and consequences of her decision. The Court of Appeal even went so far as to declare that the MHA was not meant for detaining people whose decisions are seen as peculiar, strange, or contrary to the majority of the population. Even if the person has been detained under a detention order, that person could not be compelled to accept treatment that was not related to his or her mental health if he or she is mentally competent to decide. Under the MHA (under which S was temporarily detained), a mentally disordered person can be compelled to undergo treatment connected to their mental illness. But that was not the situation in this case. Even though S may have had a mental disorder following medical assessments, she did not lack the capacity to consent to or refuse treatment not related to the disorder; accordingly, her refusal should be upheld.

S's autonomy was still respected, despite the dire circumstances. Compared to Ms B, whose situation is more likely to stir people's empathy to come to accept why she refused continued ventilation, S's adamant refusal is out of the ordinary, reasonable contemplation of most people. Even though her death was readily preventable, her refusal still had to be respected. The treatment proposed by S's doctors was standard for impending birth and could save her life. The right to autonomy is not weakened because S's decision seems to be morally repulsive.

These two decisions illustrate several qualities of contemporaneous refusals that render them legally binding. Firstly, if the person is mentally capable of deciding and,

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[4] *St George's Healthcare NHS Trust v S* [1998] 3 WLR 936 (CA); [1998] 3 All ER 673 (CA).

secondly, the person understands the nature and consequences of the refusal, being aware of the information and understanding this information to come to a decision, the person is entitled to refuse treatment, even if that results in the person's death and even if treatment would result in full recovery of health. Objective considerations of best interest are irrelevant in both decisions, because as long as the patient is mentally capable, the decision to refuse must be respected.

These two decisions also reveal the courts' approaches towards binding contemporaneous refusals. In a contemporaneous refusal context, a person is mentally competent when the person has been assessed as having understood the nature and consequences of the refusal and had voluntarily refused treatment. In both cases the doctors went to considerable lengths to determine whether they were competent to refuse treatment. The courts approached the issue of capacity by reference to the doctors' assessment of capacity in order to ascertain whether the patients were mentally competent when they expressed their refusal. This suggests a link between mental capacity and autonomy. S was presumed to be not autonomous when she refused to deliver her baby via C-section as well as standard life saving procedures at the risk of death.

S and B had shown the doctors that they had understood what they were refusing and appreciated the consequences of such refusals. This was possible given that applications were brought before the courts while they were still conscious and alert, giving the courts the opportunity to confirm their refusals. Given the grave consequences of their refusals, it would be unlikely that the Court would have accepted their refusals if they were not based on a full understanding of the nature and consequences of refusal.

Finally, their refusals were directed at specific treatments they needed at that time. As such, they were current decisions that were directly applicable because they were clear and specific. They were not based on speculations or intended to apply at some future, unspecified point. Thus, there was little room for subsequent changes to occur. Even if, assuming that S and B did change their minds about refusing treatments, they would have the opportunity to convey their revocations to the doctors.

I have sought to canvass the main issues and approaches of the courts in the context of a contemporaneous refusal which was accepted as legally binding. The legal approaches discussed earlier revealed that ADs were not always accepted as legally binding on the doctors. A treatment refusal underscores the competing principles between a person's assumption of risk in the exercise of autonomy and the sanctity of life. The laborious process undertaken by the courts in ascertaining that the refusals were genuinely made supported the notion that the non-interference model of autonomy no longer applies in reality. It indicates a move towards an approach where a person wishing to make an AD is supported appropriately in the process of making the AD. While the courts were concerned about the validity and application of the ADs, an important point that needs to be considered is the underlying differences between a contemporaneous refusal and an AD. Their distinctive characteristics are explored below.

4.2 The Distinctions Between a Contemporaneous Refusal and an Advance Refusal: Two Diverging Spectrums of Decision-Making

The dominance of autonomy within medical law and ethics, particularly in contemporaneous refusals, has quite naturally found its way into advance refusals. An AD may be regarded as simply an extension of contemporaneous refusals; however, such assimilation is misconceived. While they do share similar features, they each possess distinct characteristics. The following section examines these characteristics through Andrew and Benjamin, hypothetical characters created to illustrate the decision-making paradigms and the in-between spectrums. I will also utilise judicial decisions where appropriate and relevant to illustrate the differences between contemporaneous refusals and ADs. For the purposes of the following discussion, I designate ADs similar to Andrew's or exactly like Andrew's as A-type AD, while ADs similar to Benjamin's is B-type AD.

4.2.1 The Contemporaneous Refusal Spectrum

(a) *Andrew and the surgery*

Andrew, a 75-year-old retired navy man, was scheduled for an angioplasty surgery under general anaesthesia. He was assessed by the doctor prior to the surgery and the doctor was satisfied that he was competent to consent to the procedure and that he had understood the nature and risks of the procedure. The discussion also involved what Andrew would want if complications arose, where open heart surgery was the only option. Andrew informed the doctors that he did not want the open heart surgery under any circumstances because he did not want to assume the risks of stroke and disability, as well as becoming permanently dependent on life support. Andrew was adamant that he would only consent to angioplasty, as it was a comparatively minor procedure compared to an open heart surgery. He said that if it goes wrong, he would rather die than run the risk of serious adverse consequences arising from an open heart surgery. He said that he would not change his mind about it.

Once he was inside the operating theatre, the surgeon explained to him again about the procedure and the risks, reminding him about and reconfirming his refusal. Once Andrew had confirmed this, he was referred to the general anaesthetist. The general anaesthetist then explained the procedure and obtained his consent. Both the surgeon and general anaesthetist were satisfied that Andrew was competent, had understood the nature of the surgery and the consequences of his consent and refusal. He was then anaesthetised and the operation commenced. The surgery went well initially, but later a serious adverse event eventuated. They could save him, but it meant that he had to have the open heart surgery, which he had staunchly refused. Would the refusal continue to bind the doctors, preventing them from doing open heart surgery to save his life?

(b) *Observations*

Andrew's case embodies the qualities of a contemporaneous refusal which binds the doctors. There is the opportunity for the medical team to verify Andrew's mental capacity if they were looking for proof of his capacity, a time for him to reflect upon and understand the information conveyed to him, and then come to a decision. His consent and refusal had been obtained during consultations and verified just minutes before he became unconscious under general anaesthesia. There was more confidence about his mental capacity than a person who has not been assessed by a surgeon or a doctor under similar circumstances as Andrew and his decision. The doctor's actions in ensuring that Andrew understood what he was refusing seems to suggest that the doctor wanted positive proof of his mental capacity rather than presuming that he was mentally competent. That is, despite the presumption of capacity, the fact seems to be that in cases involving potentially life threatening decisions, doctors (and courts) will look for evidence that the patient knows and understands what they are doing. What Andrew went through was similar to what *Mr All Means All*, *Ms B*, *Ms S* and *Mr C* went through—demonstrating that he was mentally competent to refuse the open heart surgery.

Given the short space of time between the consultation and the surgery, there had been less likelihood of Andrew changing his mind compared to a refusal which is contemporaneous with the treatment decision, such as a conscious patient who refuses a blood transfusion. There was no other change of circumstances in Andrew's medical treatment and beliefs. It was very likely that his refusal would bind the doctors. Additionally, Andrew's refusal is a specific refusal by a competent person and in circumstances where the treatment options were discussed and the anticipated adverse event occurs. It was a refusal made in contemplation of a specific medical treatment, which the doctors respect because he was competent, had acted voluntarily and had understood the nature and consequences of the refusal.

If most cases were similar to Andrew's, there would be little hesitancy in upholding ADs. However, most cases are unlike his where each component of the refusal was satisfied. The next section demonstrates a situation dissimilar to Andrew and his refusal.

4.2.2 The Advance Refusal Spectrum

(a) *Benjamin and his AD*

Benjamin was a 25-year-old freelance writer. He was relatively healthy and had been known among his family and friends as a fiercely independent person. He had survived many mishaps, ranging from traffic accidents to hiking falls. He had a concussion after knocking his head in a mountain-biking activity which had plagued him with severe headache. He was discharged after a day's rest in the hospital each time it became unbearable. The doctors who examined him did not think that the headache was a result of the concussion but prescribed painkillers to him. Benjamin had a peculiar aversion to blood since he was a teenager, after hearing about transfusion-related deaths among his close relatives. He was very young when he heard about the deaths, but he did not enquire further. Benjamin was not aware of the much reduced risks with blood transfusions since his relatives' passing.

A few months ago, while covering a health-related event for his writing assignment, he heard about advance directives. Benjamin immediately took that as an opportunity to make clear his aversion to blood transfusion. He created his own wallet-sized template for his AD, which expressed that he would not want any blood transfusion under any circumstances. He then signed and dated the form. Feeling assured having completed this task; he tucked the card in his wallet and carried it with him all the time. He told his parents about his AD over a casual telephone conversation. They were alarmed but did not think that Benjamin was serious about it. Six months later, Benjamin got another writing assignment. This time he was assigned to cover a car racing event. He was standing very near to a particular bend while interviewing several spectators. Unfortunately a car that had veered out of control crashed into the bend where Benjamin was standing. Benjamin was rushed to the nearest hospital. He was bleeding profusely and had become unconscious although still breathing weakly. In the midst of preparing him for surgery the emergency doctor found his AD. He would certainly die without blood transfusion, which was needed for the life saving surgery. Should they comply with Benjamin's AD?

(b) *Observations*

The medical team faced major uncertainties with Benjamin's AD. The refusal, although specifically addressed to blood transfusion, was unclear as to its applicability. It was compounded by the vague expression "any circumstances" that he had intended to apply. Blood transfusion is a life-saving treatment and given his circumstances he would certainly need it. The doctors did not know whether Benjamin had the benefit of explanation from doctors regarding the benefits and risks of blood transfusion. They did not know if he had contemplated the consequences and under what circumstances it had been made. Similarly, they would be unable to clarify the procedure that he had refused, especially what he meant by "under any circumstances." Did he really mean to refuse blood transfusion at all cost? Had he actually understood the implications of his AD? Was it within his contemplation or had he expected that he would rather die than being subjected to blood transfusion? Even if, assuming that he is aware of the effect of his refusal, there is no evidence to indicate that he knows. This is one of the problems that arise when a person such as Benjamin did not get medical advice when he was making his AD.

There would also be a question about his mental capacity, particularly given his refusal related to standard procedures. They were unsure whether Benjamin was mentally competent when he made the AD and under what circumstances it had been made. They would not know about the fact that he had suffered a concussion prior to this accident or to what extent the concussion had affected his mental capacity to make the AD. While the presumption of capacity applies in law, it is doubtful whether such is practiced in reality. If the presumption applies, the medical team might be less quick in requiring proof that he was mentally competent when he made his AD at the first instance. They would have to accept this aspect as true until the contrary is proven. Examples where ADs were doubted because the patient's mental capacity was questionable were *NHS Trust v T* and *Re C* where the courts purportedly applied the presumption of mental capacity but had in fact required mental capacity assessments in the circumstances where it was a life and death situation presumably, or where they could not be sure that the AD represented the person's wishes.

Even where mental capacity had not been raised as an issue, a refusal of potentially life saving treatments may generate questions about the person's decision making capacity, such as in *Re T*—where the court's concern related to her voluntariness and whether she had been properly informed about alternative blood products. This is also the case with the decisions of Ms B and Ms S above where the nature of the decision may affect the application of the presumption. As they had refused life saving treatments their refusal came under scrutiny where evidence of mental capacity from psychiatrists and doctors was required.

Another aspect of validity is the provision of information at the time Benjamin makes his AD. How does the doctor know if Benjamin had really understood and processed the information in his possession? There was no opportunity to do so. Should doubts arise, it is less likely that the decision can be valid and binding. In the A-type paradigm, Andrew's surgeon and anaesthetist were able to confirm that he had understood the information, and had processed it to arrive at a decision, appreciating the procedures involved. Likewise, AK understood that he was refusing ventilation support, and had been able to appreciate what would happen when the ventilator was turned off. His doctor had explained to him the process and what would happen when the ventilator was taken away from him, that a sedative would be administered to him so that he would not be aware of the surroundings. In addition, he was given the necessary information regarding motor neuron disease and had time to reflect on it. No such evidence is available in Benjamin's case.

There could also be a possibility where a person does not base his decision on any information, or refused to accept any information at all even if information was offered to him. If Benjamin had chosen not to obtain further information because he was unaware about the relevant channels to do so, or if he thinks that it is unnecessary, that would not automatically preclude his AD from becoming binding, but it adds to the uncertainties that are present in his AD. In contrast, with a contemporaneous refusal, for example, if Andrew had waived all rights to receive information when he was in consultation with the doctor for the impending angioplasty surgery, his doctor would be able to ascertain that that is his decision and to be satisfied that he had understood the implication of refusing to be informed and had stood by that decision. In the current situation, his doctor would only be able to presume that he had understood the information which he had based his decision upon.

There is also the issue of changes since the AD was made. In this situation, this could refer to his change of mind or changes in his personal circumstances (such as where he has married or had just entered into a romantic relationship). One of the doctors noted that it had been some six months since Benjamin made the AD. Although it was quite a recent AD, the doctor could not be sure if it still represented his wishes. Reference can be made to the *AE* case.[5] In that case, doubts were raised about the continued applicability of her AD allegedly on the basis of her changed personal circumstances affecting the root of her refusal. The court accepted AE's father's claims that she had revoked her refusal and ordered the transfusion. Although it was unknown whether she had certainly changed her mind about receiving transfusion, her alleged statement about not wanting to die when she was hospitalised, her father's evidence that she had ceased attending Jehovah's Witness church meetings and her betrothal to a Turkish Muslim man made it more probable that her circumstances had changed and her refusal revoked. Unlike AE, Benjamin was not a Jehovah's Witness, thereby discounting the possibility that a change of religious belief would implicate his AD. That is, however not the end of the dilemma. There was no evidence to suggest that he had reviewed his AD in the six months. Additionally, the doctor would still not know if he had changed his mind about receiving transfusion, had he known that it was a standard life saving procedure with minimum to no risks of injury to him. It could also be the case where he might have softened his staunch towards his refusal for whatever reasons known to him, but that had not been expressed. These changes could not be communicated to the medical team even if he did change his mind. In a contemporaneous refusal, a person can clarify, confirm or revoke the previous decision, but in an AD where the person has already lapsed into unconsciousness, there may be no way to know if the person still holds on to the same wishes due to the lack of opportunity to investigate this aspect unless someone knows about the changes happening to the person in question.

Another possibility is the changes in treatment option. In Benjamin's case, blood transfusion has become a standard procedure, which can be administered safely generally. It will be a different scenario where there is no cure for the disease when the person made the advance directive but has since become available when it is needed to treat. For example, living wills completed for the purposes of avoiding prolonged death at the time when AIDS was rampant could be inapplicable because while there is still no total cure now, there are effective treatments designed to enable people living with HIV-AIDS to live a better life than before. In *AK*'s case, there is no change in circumstances either in his belief, or the medical treatment available. Those factors are consistent and stable in his case.

It was uncertain whether Benjamin had acted voluntarily. We know that his act in creating the AD was triggered after attending a health-related event. Was he, under the circumstances, "compelled" to make the AD? It is reasonable to expect that people sometimes pursue an action in response to a certain incident. It could also be the case where a person like Benjamin had always wanted to make known specific wishes but had not found any suitable avenue to do so. Thus, having heard about the option of making advance directives, he had seized upon the chance. Whatever reason it is, these factors may have influenced Benjamin, but it cannot be ascertained whether these forces were overbearing to the extent of affecting him to arrive at a decision

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[5] *HE v A Hospital NHS Trust & AE* [2003] EWHC 1017 (Fam).

which is not genuinely his? Under the circumstances, the doctors could not establish if he had made the AD under undue influences. Reference is made to Ms T in *Re T* where one of the concerns of the court was whether her refusal to accept blood transfusion had been voluntarily made. Unlike Benjamin, T's physical and mental states were weak, rendering her more susceptible to external influences coming from her mother, compared to Benjamin who was in a relatively healthy state, with no apparent suspicions of underlying illnesses. Another example is AK, where, despite his physical disabilities and suffering from degenerative motor neuron disease, his AD refusing ventilation was upheld because it had been competently and voluntarily made.

Given a range of real doubts that arise in Benjamin's case, even if it can be established that it was valid at the time, under the various circumstances, it is highly unlikely that his AD binds the doctors, because there were too many uncertainties in his AD unlike that of Andrew's refusal in the preceding example.

Andrew's and Benjamin's cases are examples that distinguish contemporaneous refusals from ADs. Two striking features that distinguish a contemporaneous refusal from an AD are the opportunity to verify the refusal and detecting the change of mind. The ambiguities present in Benjamin's AD are too material to be dismissed. Andrew's AD about what should happen while he was under general anaesthesia for the angioplasty could easily be binding because possessed the qualities of a contemporaneous refusal, similar to the two examples of Ms B and Ms S above. His refusal happened just before the surgery and the medical team could make sure he was competent, had acted voluntarily and had understood the nature and consequences of his refusal. With Benjamin's AD, none of these things were true. As one less certainty is introduced into the paradigm, the decision becomes less certain.

Thus far I have highlighted the changes that could occur in the decision-making that departs from the clear, straightforward contemporaneous refusal paradigm. At each point in the spectrum, the differences affect the certainty and impact on the binding feature of the wishes. This illustrates a grey area in which decisions are sharply divided. Within this paradigm, there exists a range of possibilities that can eventuate. The next section demonstrates a range of cases between the two spectrums discussed. The question then remains, once the differences between the two are established, where should the line be drawn to properly demarcate the various decision-makings across the spectrum?

The differences between contemporaneous refusals and ADs warrant a different methodology to render ADs legally binding. While there are some similarities between them, they differ from one another in several aspects. The significant difference between a contemporaneous refusal and an AD is all the changes that can occur between the making of the AD and its application. The preceding discussions bring forth the challenge of determining which variable or combination of variables should determine when a decision becomes legally binding or not. The inability to verify information, competence and voluntariness does not necessarily mean that the patient was not fully informed, competent or acting voluntarily. Benjamin's AD was made under completely different circumstances and carried with it less certainty regarding his refusal. What can be done to assist Benjamin to make his AD legally binding as a way of exercising his autonomy? We look at the approach known as supported decision-making.

4.3 A Supported Decision-Making Approach to Strengthening ADs[6]

4.3.1 Origins of the Supported Decision-Making (SDM) Concept

Supported decision-making is a mechanism where persons requiring support in effecting their rights to legal capacity and communicating their wishes are supported appropriately.[7] SDM has been widely interpreted in various ways, despite an absence of a collective definition.[8] Law reformers in Victoria, Australia for example, defined SDM as "an approach to decision-making that involves providing a person with impaired capacity the support they need to make their own decision".[9] An Australian public advocate framed SDM as "a framework within which a person with a disability can be assisted to make valid decisions. The key concepts are empowerment, choice and control".[10] SDM has also been conceived as a series of arrangements, both formal and informal, designed to assist people to "make and communicate to others decisions about the individual's life."[11]

The central idea for SDM is thus helping people achieve the ability to express or decide autonomously with the appropriate support suitable for them, guided by the goal to empower them. In the context of medical decision-making, SDM advocates an enabling environment which recognises the patient's autonomy and strength-

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[6] Parts of the section were first published in 2017 25(1) European Journal of Health Law.

[7] United Nations Convention on the Rights of Persons with Disability; www.futurepolicy.org. Accessed 5 August 2017.

[8] Magdalena McGuire "Supported Decision-making forum: Summary report" (Office of the Public Advocate, 24 February 2010) at 4; Office of the Public Advocate Systems Advocacy "A journey towards autonomy? Supported decision-making in theory and practice: A review of literature" (February 2014) at 26; Terry Carney "Clarifying, Operationalising, and Evaluating Supported Decision Making Models" (2014) 1 Research and Practice in Intellectual and Developmental Disabilities 46; T Carney and F Beaupert "Public and Private Bricolage—Challenges Balancing Law, Services & Civil Society in Advancing CRPD Supported Decision Making" (2013) 36(1) UNSW Law Journal 175–201.

[9] Victorian Law Reform Commission "Guardianship Final Report" 24 (30 June 2011) at xviii.

[10] Carter, B "Supported decision-making: Background and discussion paper" (Office of the Public Advocate, Melbourne, 2009) at 9; Gavin Davidson "Supported and Substitute Decision Making under Mental Capacity Legislation: A review of the international evidence" Knowledge Exchange Seminar Series (Queens University Belfast and Northern Ireland Assembly) at 2.

[11] Ibid.

ens it through various means so that a patient can formulate and express properly autonomous wishes. This method is thus consistent with the notion of empowering a person who would otherwise not be sufficiently competent to make a decision.

SDM was originally developed to give people of diminished capacity or with cognitive disability the ability to form and express their wishes. SDM gained prominence through an international instrument, the United Nations Convention on the Rights of Persons with Disability (UNCRPD). It was adopted on 13 December 2006 and came into force on 3 May 2008.[12] The UNCRPD is aimed at addressing questions about the human rights of individuals with disabilities, particularly focusing on the ways in assisting or accommodating their needs in a range of matters, such as protecting their autonomy, exercising and enjoying their rights and social developments.[13] The UNCRPD, within the spirit of the legal framework, refers to transforming and improving guardianship laws for people with disability, affirming the concept that every person, regardless of mental capacity, has human rights.[14] As such, SDM aims to ensure that people with disability are not excluded from making decisions for themselves on their basis of incapacity. The UNCRPD envisions a paradigm shift for people with disability from "objects of charities" to "subjects with rights".[15]

The UNCRPD adopted a functional concept for SDM, where the aim is to support the person in exercising their autonomy to decide. A function-based model is wide enough to include a variety of measures aimed at assisting the person, such as probing the amount or level of support necessary for people to express their wishes.[16] This would involve information gathering and explanation of concerns affecting the individual's decision-making, interpreting or construing expressed wishes,[17] and facilitating the communication of such preferences, or acting on such preferences to

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[12] "Convention on the Rights of Persons with Disabilities" United Nations. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html. Accessed 12 August 2017.

[13] Ibid; Article 1 of the Convention provides that its purpose is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity: Nicholas Caivano "Conceptualizing Capacity: Interpreting Canada's Qualified Ratification of Article 12 of the UN Disability Rights Convention" (2014) 4 Western Journal of Legal Studies 3 at 14.

[14] Reform for these laws occurred in many jurisdictions, including Australia, Canada and New Zealand.

[15] "Convention on the Rights of Persons with Disabilities" United Nations. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html. Accessed 12 August 2017.

[16] ALRC Discussion Paper 81 "Equality, Capacity and Disability in Commonwealth Laws" (May 2014) at 77 [4.9].

[17] "Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and Its Optional Protocol Nº 14—2007 From Exclusion to Equality: Realizing the Rights of Persons with Disabilities, Secretariat for the Convention on the Rights of Persons with Disabilities" United Nations Department Of Economic and Social Affairs (UN-DESA) Division for Social Policy and Development, New York, Secretariat for the Convention on the Rights of Persons with Disabilities Office of the United Nations High Commissioner for Human Rights (OHCHR) Chapter 6: from Pro Visions to Practice: Implementing the Convention at 89, 90.

the fullest possible extent.[18] Advocates of SDM are of the view that the existence of mental disorders neither implied incapacity nor affected competence in decision-making and the disabled has every right to be autonomous in aspects affecting their life.[19] Consequently, if a person can appreciate the nature of the matter, whether financial, health or risks involved, then the person could not be said to be incapable of deciding the matter.[20] Amita Dhanda construed the UNCRPD framework as broader than simply addressing the needs of individuals with disability; and that it should be interpreted as an element of the human rights framework widely applicable to medical and health matters for people with cognitive disability, social care and welfare to personal decisions, guardianship matters and living arrangements for the disabled.[21] This understanding can also, arguably, include individuals who may be suffering from temporary incapacity arising from physical or mental disorder.

Given that research on SDM has primarily focused on advocating SDM in supporting people with intellectual or cognitive disabilities in expressing their preferences in decisions affecting their lives and its efficacy,[22] it becomes important to examine its potential application to other areas.[23] In order for SDM to be capable of a

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[18] Magdalena McGuire "Supported Decision-making forum: Summary report" (Office of the Public Advocate, 24 February 2010) at 4.

[19] EW Maina "The right to equal recognition before the law, access to justice and supported decision making," CRPD COP (New York, 2009); L Waddington "A New Era in Human Rights Protection in the EC: The Implications of the UNCRPD for the EC" http://ssrn.com/abstract=1027872. Accessed 5 June 2015.

[20] Ibid.

[21] Amita Dhanda "Constructing A New Human Rights Lexicon: Convention on the Rights of Persons with Disabilities" (2008) 8 SUR—Int'l J on Hum Rts 43 at 44.

[22] M Bach and L Kerzner "A New Paradigm for Protecting Autonomy and the Right to Legal Capacity" Law Commission of Ontario (October 2010); S Pathare and L Shields "Supported Decision-Making for Persons with Mental Illness: A Review" (2012) Public Health Reviews 34; Advocacy for Inclusion "Supported Decision Making, Legal Capacity and Guardianship: Implementing Article 12 of the Convention on the Rights of Persons with Disabilities in the Australian Capital Territory" (August 2012); Amnesty International *Capacity, Supported Decision Making, Advance Directives and Substitute Decision Making: the Right to Equal Recognition Before the Law-Legal Capacity* (2011); Wallace, M *Evaluation of the Supported Decision Making Project* (Office of the Public Advocate, Amnesty International Ireland, November 2012); Terry Carney "Supported Decision-Making for People with Cognitive Impairments: An Australian Perspective?" (2015) 4 Laws 37–59; Anna Arstein-Kerslake "An empowering dependency: exploring support for the exercise of legal capacity" (2014) Scandinavian Journal of Disability Research 1; J Craigie "A Fine Balance: Reconsidering Patient Autonomy In Light of the UN Convention On The Rights Of Persons With Disabilities" (2015) 29 Bioethics 398; M Browning, C Bigby and J Douglas "Supported Decision Making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice" (2014) 1 Research and Practice in Intellectual and Developmental Disabilities 34; J tenBroek "The United Nations Convention on the Rights of Persons with Disabilities: Toward a New International Politics of Disability" (2009) 15 Texas Journal on Civil Liberties & Civil Rights 33; N Devi "Supported Decision-Making and Personal Autonomy for Persons with Intellectual Disabilities: Article 12 of the UN Convention on the Rights of Persons with Disabilities" (2013) 41 Journal of Law, Medicine & Ethics 792.

[23] Terry Carney "Clarifying, Operationalising, and Evaluating Supported Decision Making Models" (2014) 1 Research and Practice in Intellectual and Developmental Disabilities 49.

wider application,[24] a modification to the way it is utilised while retaining the aim of assisting people is necessary. It is recognised that human beings are social in nature; interacting, receiving or giving support in one way or another in a variety of activities in daily life and decision-making.[25] These can range from, for example, making financial decisions or holiday choices to switching careers. In respect of making ADs, the *disability* here refers to an anticipated future time where the individual has become incapacitated. In the case of a person whose mental capacity is not doubted, it refers to the person's inability to entirely predict the changes that may be likely to occur after making an AD. On the other hand, in the case of a physically disabled or mentally impaired individual, the disability refers to the obstacles faced in carrying out any physical tasks or mental activities. Therefore, the more complex the subject matter is, the more assistance is necessary to support the decision-making process. The main difference is in the nature of the subject matter, the support required to give effect to the decision and the ability to change their minds after the decisions become effective.

SDM principles recognised that in stark contrast to the notion of a pass or fail determination of capacity; capacity is relational: meaning that not only do we make decisions interdependently but that doctors, and other support networks have a vital role in creating relationships which support people's autonomy.[26] As such, it considered the multifaceted nature of social interactions within families or communities.[27] Additionally, SDM acknowledged that while capacity can be developed, it too can be suppressed, which paves the way for clinicians to have roles in ensuring multiple ways of communicating, perhaps facilitating discussion involving the person's own networks and using decision aids, as well as identifying if anyone is pressuring the person in the decision-making process. As such, traditional mental capacity determinations in health, including creating ADs could benefit from the SDM principles as opposed to the current, much more limited functional capacity test, which, as evident from the cases, suffers from questions of what is a 'rational' choice, and favours cognitive testing as opposed to recognising the roles and presence of emotions, wishes, or lifestyle preferences in decision-making.

The concept of SDM has its basis in human rights, rooted in the right to self-determination. Thus it is a product that develops from the move towards autonomy. It is the recognition that humans possess intrinsic dignity which warrants respect and the giving or refusing of consent to protect bodily integrity is that expression of autonomy. It requires external positive actions or support person to accommodate the person's needs to achieve the ability to exercise autonomy and realise the right to decide.

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[24] Examples where SDM would be capable of wider application include other aspects of forward planning such as will making and the appointment of attorneys for financial or personal matters; but a consideration of these applications is beyond this thesis.

[25] Anna Arstein-Kerslake "An empowering dependency: exploring support for the exercise of legal capacity" (2014) Scandinavian Journal of Disability Research 1.

[26] T Carney and F Beaupert "Public and Private Bricolage—Challenges Balancing Law, Services & Civil Society in Advancing CRPD Supported Decision Making" (2013) 36(1) UNSW Law Journal 175.

[27] Ibid.

Human dignity as empowerment is a notion that is consistent with the developments of autonomy, in which the control in medical decision-making is shifted from the authoritative, paternalistic hands of doctors, towards patients.[28] SDM as such has the potential to offer an influential policy for change.[29]

4.3.2 SDM Approach: The Preferred Method to Creating ADs

The controversies and challenges to establishing with certainty that the AD represents the person's prior preferences provide a timely opportunity for SDM to apply. The majority of the courts' concerns in AD disputes focussed on four issues: first, whether the patient had mental capacity at the time the AD was made; second, whether the patient had understood the nature and consequences of the refusal, based on the types of information available, third, what the AD meant in the circumstances that had arisen and fourth, whether the AD still represented the patient's wishes.

SDM employed *at the time the AD was made* could address the first two concerns. In a contemporaneous refusal, capacity, even if not presumed, can be examined contemporaneously, a situation which is not possible in an AD. As such, SDM provides the opportunity for a person to be seen or have his capacity to be assessed by a doctor, or referred to an appropriate specialist for such assessments. Secondly, the discussions that occur in the consultation include providing relevant information to the person about the treatment refused. The discussion can enlighten the person about the nature and consequences of their refusal and the possibility that changes in their personal circumstances, that may or may not lead to changes of mind, may occur. Thirdly, the impact of the changes in circumstances should then be explained to the patient. This includes an explanation to the patient that there is a real possibility that these changes in the personal circumstances may eventuate at some future time which may not have been anticipated at the time of making the AD. The patient then has the opportunity to appreciate that the AD needs to cater to these possibilities, or at least to recognise that the AD may afford no opportunity for a change of mind or a reflection of changed circumstances when the person becomes incompetent.

The use of a support person at the time of making the AD can be helpful at the time of implementation. For example, the families of AK and XB were able to confirm the wishes of the respective patients because of their involvement in the AD making process. Their involvement allowed them to have a better understanding of the patients' decisions, which is especially crucial when it comes to implementing the terms of the AD. They can provide information to questions raised about the personal circumstances of the patients that might be relevant to implementing the

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[28] Empowerment is based on the intrinsic human dignity idea, and the freedom entitled to everyone, which respects personal autonomy; Beryck Beyleveld and Roger Brownsword *Human Dignity in Bioethics and Biolaw* (Oxford University Press, 1993) Oxford Scholarship Online: March 2012. https://doi.org/10.1093/acprof:oso/9780198268260.003.0001.

[29] Mary Donnelly, 'Best Interests In The Mental Capacity Act: Time To Say Goodbye? 2016 Medical Law Review, 24(3) pp. 318–332.

AD and whether any subsequent changes have arisen that would affect the AD. Finally, through the discussion, the person can consider the possibility of nominating a substitute decision-maker or a trusted person to deal with the implementation of the AD in the event of conflict between family members.

SDM is uniquely appropriate to accommodate the distinctive characteristics of ADs. It pre-empts the uncertainties by reducing some practical obstacles and doubts towards achieving a person's expression of autonomous wishes, resulting in a greater likelihood of the AD being legally binding and the person's wishes being respected. SDM thus supports competent people in making better and more informed decisions. It is a practical, pro-active method that helps people achieve their preferred choice, rather than the existing approach adopted by the courts that acted as a "gatekeeper" by determining the validity of a decision either through a demonstration of mental capacity or understanding of the nature and consequences of refusal. The question of mental capacity is itself subject to debate, as there does not appear to be a single, universally accepted definition across the legal, psychology and mental health fields.[30] SDM provides a mechanism in which a person can be supported to achieve the requisite capacity, according to the needs and context of the decision.

SDM is likely to involve health professionals and family or friends. This is especially true with patients such as AK and XB, whose physical disabilities render them liable to be assisted in expressing their wishes and recording them at the time they decided to cease further ventilation at a future specified time. This approach could also be helpful for people who are borderline competent, such as a person who could fulfil the requirements for a competent decision, but only with assistance and support. Moreover, it could assist people who are currently competent to anticipate and avoid the sorts of problems that ADs sometimes encounter. The use of SDM can provide answers to questions about the validity and whether the person still intended it to apply to the circumstances that have arisen. SDM can help accommodate the eventuality of subsequent changes occurring by introducing some measures at the time the AD is made. While the person is discussing the AD with the doctor, it is important to emphasise the significance of regular review and confirmation of the AD as the person requires or when changes occur that would impact the application of the AD.

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[30] For example, see generally Making Health Care Decisions: A Report on the Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship, Volume One: Report (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research, United States Government Printing Office, Washington DC, October 1982). See also Conor O'Luanaigh and Brian Lawlor "Drugs that Affect Competence" in Gabriela Stoppe (ed) *Competence Assessment in Dementia* (Springer, New York, Germany, 2008) at 41; Deborah Bowman "Who decides? Ethical Perspectives on Capacity and Decision-making" in Gabriela Stoppe (ed) *Competence Assessment in Dementia* (Springer, New York, Germany, 2008) at 51, 52, 53. Deborah Bowman argued that capacity is a fluctuating concept in reality where the patient's capacity operates on a continuum according to the surrounding factors, as opposed to the legal determination. Thus Bowman pointed out that an assessment of whether a person is mentally competent or otherwise required a consideration of the kind of treatment and the decision to be made.

This concept thus enables the person to retain the power as the decision-maker,[31] enhancing rather than diminishing a person's autonomy.[32]

SDM can potentially help the AD become more likely to be legally binding in a jurisdiction where the legal status is unclear. This is the case in jurisdictions where no statute is in place and the common law applies, for example, in New South Wales and Tasmania in Australia where the common law applies in the absence of statutory provisions. It can also apply in jurisdictions that recognise certain formalities for ADs to be legally binding, such as in England where ADs refusing life sustaining treatment bind doctors when such AD is written, signed, witnessed and verified to the effect that it applies even if life is at risk. It will also ensure compliance with the formal requirements set out in the law by including the necessary support to meet the formalities.

4.3.3 Empowering Patients Through SDM: The Autonomy Framework in ADs

Advance directives are underpinned by the principle of autonomy. Although autonomy has been closely associated with an individual's self-determination in its contemporary meaning, it initially referred to groups of autonomous entities rather than individuals.[33] This concept has since been applied in various fields and an autonomous being acts without restraint in accordance with a self-selected plan similar to how a sovereign government administers its land with its own plan,[34] in the process assuming the risks and benefits of the chosen path.[35] SDM builds on the notions of empowering people, through exercising their autonomy in expressing their wishes. We have seen how the social developments of the time have provided a suitable platform for issues on patient rights to flourish and an environment that fosters the rise of ADs. Notions challenging the authorities' power over individuals, increasing awareness of civil rights, and the feminist movements, added to accepting and defending autonomy and the self.[36] The idea of self and the importance of indi-

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[31] Robert D Dinerstein "Implementing Legal Capacity under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making" (2011–2012) 19 Hum Rts Brief 8 at 10.

[32] Amita Dhanda "Constructing A New Human Rights Lexicon: Convention on the Rights of Persons with Disabilities" (2008) 8 SUR - Int'l J on Hum Rts 43 at 48, 50.

[33] Lolle W Nauta "Historical Roots of the Concept of Autonomy in Western Philosophy" (1984) PRAXIS International 363 at 367.

[34] Tom L Beauchamp and James F Childress *Principles of Biomedical Ethics* (7th ed, Oxford University Press, New York, 2013) at 101.

[35] Marina Oshana *Personal Autonomy in Society* (Ashgate Publishing Limited, England, 2006).

[36] David J Rothman "The Origins and Consequences of Patient Autonomy: A 25-Year Retrospective" (2001) 9 Health Care Analysis 255 at 255, 256.

viduality became a forceful message in asserting autonomy,[37] in part influenced by lawyers through patient negligence suits and judicial decisions, where informed consent became synonymous with autonomy.[38] It has become clear that autonomy has assumed an important place in law and society.

I consider two influential concepts of autonomy which have greatly influenced the modern understanding and application of autonomy, especially in bioethics and medical law. They are Immanuel Kant and John Stuart Mill. Kantian and Millian ideas on autonomy and liberty have been interpreted and applied in various fields. In addition to these two concepts, the guiding ethical principles popularised by Beauchamp and Childress will be considered.

4.3.3.1 Rational Autonomy

Immanuel Kant's most influential work, the *Groundwork of the Metaphysics of Morals* was published in 1785. Other prominent publications include *Critique of Pure Reason* published in 1781 and the second edition of the same title in 1787 and 1788. The formulation of autonomy was explored in *The Groundwork of the Metaphysics of Morals*. The autonomy of the will is conceived as "the property a will has of being a law to itself (independently of any property of the objects of volition)"[39] which has been interpreted as not doing whatever a person likes, but rather to mean accepting "unconditional principles of rational choice and action independently of their inclinations, as their own standards"; in other words, acting as rational agents[40] and being responsible for their actions.[41] Kant viewed human reason as a guiding compass that helped discern between good and evil and an action's consistency with duty.[42] Kant's formulation of autonomy is presented as[43]:

> This principle of humanity, and in general of every rational agent, as an end in itself (a principle which is the supreme limiting condition on every person's freedom of action) is not borrowed from experience: first, because it is universal, applying to all rational beings generally, and no experience is sufficient to determine anything about all such beings; secondly, because in this principle we conceive of humanity not as an end that one happens to have (a subjective end)—that is, as an object which people, as a matter of fact, happened

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[37] Alfred I Tauber "Historical and Philosophical Reflections on Patient Autonomy" (2001) 9 Health Care Analysis 299 at 302.

[38] David J Rothman "The Origins and Consequences of Patient Autonomy: A 25-Year Retrospective" (2001) 9 Health Care Analysis 255 at 256, 258; Ian Kerridge, Cameron Lowe and Cameron Stewart (eds) *Ethics and Law for the Health Professions* (4th ed, The Federation Press, NSW, 2013) at 128 on correcting the imbalance of the power between doctor and patient through the introduction of informed consent as a means of protecting the autonomy of the patient.

[39] Kant *Groundwork for the Metaphysics of Morals* Translated by Arnulf Zweig and edited by Thomas E Hill, Jr and Arnulf Zweig (Oxford University Press, US, 2002) at 92; G 4: 440.

[40] Kant *Groundwork for the Metaphysics of Morals* Translated by Arnulf Zweig and edited by Thomas E Hill, Jr and Arnulf Zweig (Oxford University Press, US, 2002) at 92.

[41] Ibid, at 95.

[42] Ibid, at 205; G 4: 404.

[43] Ibid, at 231; G 4: 431.

> to make their end. We conceive of it rather as an objective end—one that, as a law, should constitute the supreme limiting condition on all subjective ends, whatever those ends may be. This principle must therefore spring from pure reason.

For Kant, autonomy was important because "autonomy is the foundation of human dignity and the source of all morality."[44] Autonomy was vital "in particular for the idea that rational nature in every person ought to be treated as unconditionally valuable, above all price."[45] Kant believed that human beings are possessed of values and able to act in ways that animals do not and cannot.[46]

An autonomous person, in Kant's view, is one who is able to select a course of action independently of desires that arise as a human being. Kant's claim rests upon the basis that "morality centres on a law that human beings impose on themselves, necessarily providing themselves in doing so with a motive to obey."[47] An attribute that can be drawn from Kant's notion of autonomy is that a person is autonomous if he is rational. The person must not be moved by fear of punishment or desires, free from external and internal pressures. Kant's conception of a rational, autonomous agent was influenced by Christian Wolff, an Enlightenment scholar who emphasised knowledge as enabling individuals to be self-governing,[48] and the writings of Hume and Rousseau.[49] A Kantian rationality perspective can be summarised as follows[50]:

> Kantian autonomy presupposes that we are rational agents whose transcendental freedom takes us out of the domain of natural causation. It belongs to every individual, in the state of nature as well as in society. Through it each person has a compass that enables common human reason to tell what is consistent with duty and what inconsistent. Our moral capacities are made known to each of us by the fact of reason our awareness of a categorical obligation that we can respect against the pull of desire. Because they are anchored in our transcendental freedom we cannot lose them no matter how corrupt we become.

Thus, an autonomous person in Kant's view is one who is rational, uninfluenced by internal or external desires, capable of making judgements according to universally acceptable rules governing their behaviour. This suggests a rather challenging level of personal self-awareness and control of desires in making decisions or pursuing a course of conduct. It does not merely require a person to acknowledge human fallibility and weaknesses, but also requires them to strive to manage, or even better, overcome such desires. Only then can a person be said to be truly autonomous. Mill's idea of autonomy differs from Kant.

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[44] Thomas E Hill Jr *Autonomy and Self Respect* (Cambridge University Press, USA, 1991) at 43.

[45] Ibid, at 30.

[46] Ibid, at 34.

[47] J B Schneewind *Invention of Autonomy: A History of Modern Moral Philosophy* (Cambridge University Press, New York, USA, 1998) at 483. For further explanation of Kant's notion of autonomy, see Henry E Allison *Immanuel Kant* The Oxford Companion to Philosophy (2nd ed, Oxford University Press, Oxford, 2005).

[48] J B Schneewind *Invention of Autonomy: A History of Modern Moral Philosophy* (Cambridge University Press, New York, USA, 1998) at 509.

[49] Ibid, at 484, 485, 509.

[50] Ibid, at 515.

4.3.3.2 Personal Liberty and Non-interference

John Stuart Mill's life was said to embody his beliefs.[51] He believed that men were human because they were capable of choosing.[52] Mill's most celebrated belief in liberty was outlined in his essay *On Liberty*, "Over himself, over his own body and mind, the individual is sovereign."[53] Mill's conception of personal liberty extends beyond state interference, and into the realms of individual space and private matters. Mill valued liberty greatly, underpinned by the belief that men can flourish without interference in their private lives. When a person's liberty is interfered with, it will diminish the person's potential and capabilities. A person's liberty can only justifiably be limited when his or her actions harm other people. He took pride in the mental development of men, which should be unhindered to pursue the goods in life.

Mill's idea of liberty stemmed from identifying the struggle for personal liberty against the authority of the state and landholders.[54] He was influenced by the literature from the early French liberal ideals and "German romanticism" which contributed to his conception of liberty and the uniqueness of "human nature as the seat of individuality and autonomy."[55] According to Mill, setting a limit to the appropriate interference by the majority over individual independence is important to securing a good condition for human activities.[56] The reason Mill prized liberty so much is that if humans are obstructed from developing their mental faculties, they would be no different than animals or machines and consequently, the nation could not progress and flourish. He reasoned that "the mental and moral faculties are improved only by being used."[57]

The distinctive endowment of human beings—the mental faculty and ability to think and reason sets human beings apart from the rest. He gave an example of following customs. Mill reasoned that when a person followed a custom blindly, the person did not exercise any judgements "in discerning or in desiring what is best" according to the circumstances.[58] Hence, permitting other people to dictate and choose what is deemed the best for the person is akin to treating the person as an animal. Mill reasoned that whilst a person can be steered out of harm's way by guidance, any action that was more intrusive than advice or guidance, such as threatening to harm that person if the guidance was not followed, would undermine the person's worth as a human being.[59] Therefore, in deciding whether to follow the guidance or not, the person would need to exercise his mental judgement, and form

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[51] Isaiah Berlin *Four Essays on Liberty* (Oxford University Press, London, 1969) at 174.

[52] Ibid, at 192.

[53] John S Mill *On Liberty* (James R Osgood and Company, Boston, MA, US, 1871) at 23.

[54] Ibid, at 8.

[55] John Skorupski *The Oxford Companion to Philosophy* (2nd ed, Oxford University Press, Oxford, 2005).

[56] John S Mill *On Liberty* (James R Osgood and Company, Boston, MA, US, 1871) at 14.

[57] Ibid, at 112, 113.

[58] Ibid, at 112, 113.

[59] Ibid, at 114.

his own reason. If he did not utilise his mental faculties to arrive at a decision, and merely followed such guidance, then he would be similar to an animal—"inert and torpid, instead of active and energetic."[60]

The ability to decide is important to Mill. According to Mill, a person who decides for himself is a person who utilises his entire ability. Therefore, children and mentally incapacitated people are excluded from exercising this right.[61] In making a decision, Mill envisioned that a person would possess several qualities in exercising their mental ability towards achieving that decision. This can be concisely summed up as follows[62]:

> He must use observation to see, reasoning and judgment to foresee, activity to gather materials for decision, discrimination to decide, and when he has decided, firmness and self-control to hold to his deliberate decision.

Closely associated to the idea of exercising the mental ability to decide is the means towards achieving a particular decision. Mill reasoned that[63]:

> It is possible that he might be guided in some good path, and kept out of harm's way, without any of these things. But what will be his comparative worth as a human being? It really is of importance, not only what men do, but also what manner of men they are that do it. Among the works of man, which human life is rightly employed in perfecting and beautifying, the first in importance surely is man himself.

Individuality and the ability to exercise mental faculties are the hallmark of liberty and autonomy according to Mill. Apart from the ability to exercise mental faculties, another reason for distinguishing human beings from animals is their individuality. In Mill's thinking, human beings have the potential to achieve great heights and their individuality deserves respect.[64] He equated individuality with human development and believed that encouraging individuality produced well developed human beings.[65] Mill valued a person's individuality and encouraged individual spontaneity to flourish and be valued.[66] Except for the legitimate interference, a person's consciousness which constitutes the most private domain of all must not be encroached at all.[67] Mill reasoned that individuality increased a person's worth, which then became valuable to other people.[68] The ability to express a person's individuality does not necessarily entail a blanket permission to act freely to the extent of harming others. Mill thought it permissible to impose punishment on people, using the example of a

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[60] Ibid, at 113.

[61] Ibid, at 24.

[62] Ibid, at 113.

[63] Ibid, at 114.

[64] Ibid, at 109, further "the free development of the individuality is one of the leading essentials of well-being".

[65] Ibid, at 123.

[66] Ibid, at 110.

[67] Ibid, at 27, 28. Mill considered that actions that harm the others can be legitimately interfered with, because "for whatever affects himself, may affect others *through* himself".

[68] Ibid, at 121.

mob gathered in front of the house of a corn dealer.[69] Mill could also be regarded as a social utilitarian concerned with legal and social reform for individual and social good within a liberty construct, illustrated through the example of the society legitimately withholding support for public figures that disrespect individuality.[70]

Mill's notion of autonomy is one that prohibits coercive or threatening external interference upon an individual, which amounts to disrespecting the individual's dignity. The person must exercise his entire faculties to decide the best course of option to pursue. It operates on the basis that the person possesses the physical and mental abilities to exercise his wishes independent of other support. While Mill was mostly concerned with a non-interference "liberty" concept of autonomy, he was at least open to the idea that persuasion and advice could be consistent with an autonomous decision, provided the individual ultimately applied his reasons to the decision and that such advice did not override the individual's reason. The question is always about whether the influence is so overbearing as to undermine autonomy, but a degree of influence or advice is generally regarded as acceptable, maybe even as intensely valuable.

Both Mill and Kant perceived autonomy as important because of human worth and dignity; that the person is capable of thinking and acting, and becoming their own agent. While Kant is of the view that man cannot be the means and end to the people, and actions that are morally worth pursuing are the ones that are universally applicable, Mill's idea of liberty has come to be associated with a negative non interference type. Kant's conception of autonomy requires a process of rationalisation based on the freedom of reason.

Mill's influential association with a negative non-interference approach of autonomy gained prominence in the modern understanding of medical law. The more influential non-interference notion of autonomy was viewed favourably in the aftermath of the Nuremberg trial and subsequently following other medical research scandals that erupted in different parts of the world. The time was ripe for such aspect of non-interference to apply. This emphasis on non-interference is incomplete because another aspect of Mill says a person must possess and exercise their mental capacity in order to arrive at a decision. It is therefore highly possible that Mill's idea of autonomy is more than non-interference.[71] It presupposes a person to possess some degree of mental capacity and presumably does not preclude support necessary to enable a person to achieve autonomy.

Kant required, possibly, a higher degree of rationality in an individual to qualify as autonomous, thus setting a more demanding standard for genuinely autonomous actions compared to Mill. For Mill, as long as a person exercises his mental powers to arrive at a decision, even if that decision is detrimental to himself, or at odds with the

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[69] Ibid, at 107, 108.

[70] Ibid, at 142.

[71] Similarly, Bach and Kerzner in Michael Bach and Lana Kerzner "A New Paradigm for Protecting Autonomy and the Right to Legal Capacity" Law Commission of Ontario (October 2010) at 40 interpreted Mill's understanding of autonomy as not entirely excluding *any* assistance in the decision-making process.

majority views or universal ideas, that person is still entitled to make such decisions and considered as an autonomous being. Kant, in addition, requires a person to not only possess the mental ability to decide, but to ensure that the decision conforms to the universal laws to be morally right. While a person can still be considered as autonomous if the decision is motivated from an internal desire in Mill's view, such a person is not autonomous from Kant's perspective. This person has to control both his internal and external desires so as to arrive at a decision.

Kant as with Mill, presumes a person to possess a certain standard of mental capacity, rational thought, but Kant goes further than the basic individual capability. He demanded that the individual concerned consider whether his actions would be accepted as universal rules and consistent with moral worth and behaviour. This would preclude the majority of population to possess the mental capacity in order to exercise an autonomous choice. Kant's conception of autonomy thus may pose challenges in the context of ADs.

4.3.3.3 The Four Principles: Autonomy, Non-maleficence, Beneficence and Justice

Beauchamp and Childress are influential scholars in articulating the four main ethical principles governing bioethics—autonomy, non-maleficence, beneficence and justice. Their first edition of *Principles of Biomedical Ethics,* published in 1977 was a leading treatise in bioethics, attracting much attention and debate. It had since undergone revisions to the seventh edition, addressing the challenges thrown by their critiques (particularly in respect of their "principlist" approach towards the ethical principles and the centrality of autonomy in bioethics) with modifications to the dominant ethical principles discussed.

Beauchamp and Childress gave their account of autonomy in the context of healthcare and medical research. Having considered Mill's and Kant's ideas of autonomy, they proposed a theory of autonomy based on non-ideal situations.[72] Their theory suggests that as long as the person acts intentionally with understanding, free from domineering influences causing those actions, that person is regarded as acting autonomously.[73] They argued that this interpretation of autonomy coheres with daily preferences of generally competent individuals.[74] Their conception of autonomy thus shares Mill's notion of autonomy in the aspect of non-interference. Beauchamp and Childress also recognised the distinctive nature and value of human beings. According to them, the fundamental conditions for theories of autonomy are liberty and agency, the former referring to freedom from domineering agents and the latter, the

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[72] Tom L Beauchamp and James F Childress *Principles of Biomedical Ethics* (7th ed, Oxford University Press, New York, Oxford, 2013) at 104.

[73] Ibid.

[74] Ibid.

capability for acting intentionally.[75] Respecting an autonomous person thus entails recognising the person's right to their own views and actions, and helping to promote the person's capability for acting autonomously.[76] This notion of respect for autonomy was maintained in their later edition.[77] Particularly, promoting a person's capability involves not only "respectful attitude" but also "respectful action."[78] The combination of positive and negative obligations was succinctly summarised as follows[79]:

> It also requires more than non-interference in others' personal affairs. It includes, in some contexts, building up or maintaining others' capacities for autonomous choice while helping to allay fears and other conditions that destroy or disrupt autonomous action. Respect, so understood, involves acknowledging the value and decision-making rights of autonomous persons and enabling them to act autonomously.

Beauchamp and Childress observed that this notion of respecting autonomy appeared to accord with the interpretations of modern Kantian scholars that[80]:

> [T]he demand that we treat others as ends requires that we assist them in achieving their ends and foster their capacities as agents, not merely that we avoid treating them solely as means to our ends.

There may be reason to imply that Kant's respect for human dignity which treats men as ends rather than means has been extrapolated by Kantian scholars and extended to cover positive actions in terms of capacity building and negative actions of non-interference. A more expansive notion of autonomy may not be particularly prominent when bioethics started, but may have gained some traction in recent times, although it is nowhere near as widely accepted as the negative "liberty" right.

4.3.3.4 Rethinking Autonomy in ADs: Empowerment Through the SDM Approach

SDM is premised on the notion of enabling and empowering people to achieve their ability to the fullest possible extent in making decisions. It is thus timely to rethink autonomy as understood in its popular interpretation as 'non-interference'. This current conception is predisposed to various challenges, for example, a closer scrutiny of choices with a view to ensuring they are truly autonomous and developments surrounding doctors' professionalisation.

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[75] Tom L Beauchamp and James F Childress *Principles of Biomedical Ethics* (5th ed, Oxford University Press, USA, 2001) at 57, 58.

[76] Ibid, at 63.

[77] Tom L Beauchamp and James F Childress *Principles of Biomedical Ethics* (7th ed, Oxford University Press, USA, 2013) at 107.

[78] Ibid.

[79] Ibid.

[80] Ibid. Beauchamp and Childress referred to the writings of Barbara Herman "Mutual Aid and Respect for Persons" (July 1984) 94 Ethics 577; Onora O'Neill "Universal Laws and Ends-in-Themselves" (1989) 72 Monist 341.

Autonomy generally requires that a person's decision is respected; but that decision will not necessarily be accepted at face value. In reality, patients are often asked to justify their choices in a lot more detail than the presumption of autonomy would suggest. Doctors encourage patients to think more carefully about their decisions, especially when they disagree with their doctors. These checks on their capacity to make autonomous choices leave one wondering why they are only required when the patients disagree with expert advice. The first trigger that precedes an enquiry into the person's mental capacity is, very possibly, the nature of the decision. If the decision is one that refuses life saving treatment, the patient is subject to even closer scrutiny.[81] Even those jurisdictions where legislation permits treatment refusal and ADs insist upon the test for competence as the gatekeeper for valid decision-making. Halpern criticised the existing bioethical construct of autonomy as fulfilling a decision-making capacity threshold, which precludes patients from making decisions "that doctors do not agree with."[82] Further, Halpern observed that[83]:

> Patients are not obligated to exercise their capacity for autonomy by deliberating and acting from their considered values. This means that patients have the right to make their decisions however they want to, including by flipping a coin, even though caregivers might rightfully attempt to dissuade them from doing so.

These scrutinies raise questions about the existing presumption of autonomy or the notion that refusals need not be rational as in the case of the pregnant woman in *St George's* who refused a caesarean.[84] It is particularly challenging for ADs because the opportunity to assess the patient's competence retrospectively is usually unavailable. The outcome for the pregnant woman might have been very different had she lapsed into unconsciousness despite her prior refusal. This challenge highlights the concerns that the courts have when disputes are brought before the courts, although it is possible that this type of enquiry occurs on a daily basis in medical practice. Margaret Brazier remarked on the continuing struggles faced by the law between the association of autonomy and mental capacity[85]:

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[81] Various examples from the cases on treatment refusals illustrate this point: *Re C (refusal of medical treatment)* [1994] 1 WLR 290 (Fam); and *St George's Healthcare NHS Trust v S* [1998] 3 WLR 936 (CA); [1998] 3 All ER 673 (CA). In the latter, Ms S, who refused to deliver her baby via Caesarean section, risking her unborn child's life was immediately referred to the psychiatric specialists for an assessment of her mental competence. The mental capacity of Miss T was similarly questioned when she refused blood transfusion: *NHS Trust v T (adult patient: refusal of medical treatment)* [2004] EWHC 1279 (Fam). In *Heart of England NHS Foundation Trust v JB (by her litigation friend, the Official Solicitor)* [2014] EWHC 342 (COP), Ms JB was referred to the Court of Protection for a determination of whether she was capable of refusing treatment when she decided against leg amputation.

[82] Jodi Halpern "Empowering patients is good medical care" (2013) 20(2) Philosophy, Psychiatry & Psychology 179 at 180.

[83] Ibid.

[84] St George's Healthcare NHS Trust v S [1998] 3 WLR 936 (CA).

[85] Margaret Brazier *Medicine, Patients and the Law* (3rd ed, Penguin Group, England, 2003) at 39. Similarly, Beauchamp and Childress have remarked on the proximity between competence and autonomy; see Tom L Beauchamp and James F Childress *Principles of Biomedical Ethics* (7th ed, Oxford University Press, USA, 2013) at 116.

> In setting boundaries for mental capacity the law struggles with the concept of what constitutes an autonomous choice. The temptation is strong to regard a choice you disagree with as non autonomous. The outcome of the choice should be irrelevant.

Concepts of capacity and the requirement to understand the information and appreciate the nature of the consent or refusal hardly cross the majority of the laypersons' minds when they decide. These are legal constructs created by legal scholars and the courts to aid decision-making when disputes appear before the courts. There is cogent reason to rethink autonomy and these constructs in light of the challenges for achieving autonomy.[86]

Apart from mental capacity, an aspect used to scrutinise a person's autonomous wish is the provision of information. What constitutes an autonomous consent or refusal to consent is more than the straightforward action of saying 'yes' or 'no'. A person can possibly be said to be non-autonomous if insufficient or misleading information led the person to choose otherwise than the person would not have done had the person been given the complete details.[87] The challenge then would be ascertaining whether a refusal is autonomous enough, rather than a clear line defining a perfectly autonomous refusal or not autonomous at all.

A further challenge relates to questioning whether the person has voluntarily refused treatment. Voluntariness refers to the absence of influences in the form of, mainly, coercion and manipulation.[88] Autonomy can be undermined if the person's voluntariness has been compromised by the presence of external influences, such as from families, spouses or next-of-kin, as well as religious beliefs and in cases of emergency. No choice is made in a vacuum and many sorts of influence are regarded as consistent with autonomy; so the question is when the influence has become overbearing so as to undermine any free will at all. An example of compromised autonomy is the case of a devout Jehovah's Witness who refused blood transfusion on biblical commands.[89] While the person is rational on all counts, it may be possible that the beliefs may have clouded the person's judgment because he has no freedom to venture out and explore what other religious beliefs are. It may not occur to him that his so called "autonomy" has been stripped from the very beginning when he was indoctrinated from a tender age.[90] This is quite a challenging and controversial

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[86] Grant Gillett referred to these concepts, but particularly highlighted that constructing autonomy under the concept of competence effectively legitimised "a search and disable policy" for people "who are differently oriented in the human life-world" where "the elderly and mental health survivors both of whom may be considered to suffer from a defect of volition due to mental incompetence." See Grant Gillett "How do I learn to be me again? Autonomy, life skills and identity" in L Radoilska (ed) Autonomy and Mental Disorder (Oxford University Press, Oxford, 2012) 233 at 233.

[87] *Re T* [1992] EWCA Civ 18 is an example where one of the reasons her AD was declined was because the trial court found that Miss T had been misinformed about the alternatives to blood products, and thus her refusal to consent to blood transfusion was not genuine.

[88] Tom L Beauchamp and James F Childress *Principles of Biomedical Ethics* (7th ed, Oxford University Press, USA, 2013) at 104.

[89] For example, the case of *Re T* [1992] EWCA Civ 18.

[90] *X v The Sydney Children's Hospitals Network* [2013] NSWCA 320 there is never really an autonomous decision because the child has been cocooned in faith.

situation, because on the one hand you want to respect the person's right to decide, on the other hand, it is quite possible to harbour doubts about the voluntariness of the decision owing to influences that potentially saps the person's will. The question of voluntariness is complicated because it is difficult to disentangle the personal agendas of the persuader from the views of the patient. Coercion, manipulation or persuasions are some examples of influences that render a person involuntary because it makes the person lose control.[91]

Another aspect to scrutinising the decision is examining the decision-making process. Is the consent or refusal made through a ritual that amounts merely to ticking all the boxes?[92] Herring claims that purportedly autonomous decisions can carry different moral weights, with reference to the works of John Coggon and Alasdair MacLean on the different versions of autonomy.[93] For example, it is usually assumed that a carefully considered decision, taking into account the relevant information and exercising reflective judgement, together with the moral values or beliefs of the individual carries greater weight compared to one that is less considered.[94]

Closer scrutiny is also made by measuring the gravity of the outcome of the decision with the corresponding mental capacity of the person at that time.[95] This approach suggests that the graver the decision is, the stricter is the requirement of the person's mental capacity. If a person refuses life-sustaining treatment, the evidence needs to be clear and convincing that the person possesses sufficient mental capacity to exercise that judgement, and if so then the decision will be considered as autonomous. Munby J had alluded to the question of standard of proof when he declined AE's refusal to receive blood transfusion, but did not state what the exact standard of proof was, except that it was nothing higher than the ordinary civil standard of proof which was based on a balance of probabilities.[96]

In addition to the scrutiny on the choices made by a person, there is also the challenge with a doctor's professional duties towards patients. Prior to the increasing recognition of patient autonomy, doctors practiced according to the Hippocratic tradition, which was primarily concerned with beneficence and non-maleficence. A doctor is also bound by the ethical code of conduct and professional etiquette in the discharge of his obligations towards a patient. In many parts of the world, doctors are prohibited from engaging in doctor assisted suicide, or becoming financially or

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[91] Tom L Beauchamp and James F Childress *Principles of Biomedical Ethics* (7th ed, Oxford University Press, New York, Oxford, 2013) at 104, 138–139.

[92] For example see *Hunter and New England Area Health Service v A* [2009] NSWSC 761 where the patient had ticked the box for refusing dialysis.

[93] Jonathan Herring *Medical Law and Ethics* (4th ed, Oxford University Press, UK, 2012) at 201. For example, ideal desire autonomy, best desire autonomy and current desire autonomy in the former and the libertarian, liberal and communitarian approaches.

[94] Ibid.

[95] Ibid, This is known as the concept of 'risk-relative capacity'.

[96] *HE v A Hospital NHS Trust & AE (by her litigation friend the Official Solicitor)* [2003] EWHC 1017 (Fam) at [24].

sexually involved with their patients.[97] The nature of the therapeutic relationship provides the opportunity for a doctor to help a patient enhance and promote the patient's authentic autonomy and to reach an autonomous decision.

While a doctor-patient relationship embodies a therapeutic bond, the use of different words in representing the connection creates different perceptions about the relationships. The term patient is understood to apply to most countries, while in New Zealand, as identified earlier, a patient is known as a consumer. The former implies a person who receives medical treatment, for whom healthcare professionals offer curative provisions and healing duties; while the latter suggests a more rights-driven position, where healthcare consumers are free to choose the healthcare services on offer. These differences affect the relationship dynamics; and consequently alter the imposition of duties, obligations and rights of the respective parties.

However, an increased focus on patient autonomy, if pushed too far, could result in a shopkeeper-consumer-like relationship. Raymond Tallis is critical of the notion of consumerism in the doctor-patient relationship, arguing that it is biased to view doctors as scoundrels who would conduct themselves poorly if left unregulated and that patients are often powerless victims, preyed upon by these doctors.[98] He pointed out that while medicine has empowered patients, at the same time it has disempowered them unintentionally, especially when patients do not respond to the treatment as well as they had anticipated.[99] He then articulated that a doctor can help in this context, and in a sense empower the patient, by sharing "his understanding of what is going on."[100] Doctors can also play the role of explaining information that a patient does not comprehend.[101]

In critiquing the current approach to autonomy based on the non-interference interpretation, Bach and Kerzner, proponents of SDM, argued that this approach differentiated people who could exercise autonomy from people who could not; through demonstrations of mental capacity in understanding the information and nature and consequences of their decisions.[102] They advocated that the negative and positive notions of autonomy should be viewed as "entirely interdependent", consequently, "both views are essential to a full and robust theory of autonomy."[103] Although Bach and Kerzner's argument rests in the context of mental health and disability, the notion of autonomy which is supportive of providing assistance to

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[97] For example, in respect of the prohibition of sexual relationships between doctors and patients: S G Perez, R J Gelpi and A M Rancich "Doctor–patient sexual relationships in medical oaths" (2006) 32 J Med Ethics 702.

[98] Raymond Tallis *Hippocratic Oaths: Medicine and its Discontents* (Atlantic Books, London, 2004) at 89.

[99] Ibid, at 90.

[100] Ibid.

[101] Ibid, at 98.

[102] Michael Bach and Lana Kerzner "A New Paradigm for Protecting Autonomy and the Right to Legal Capacity" Law Commission of Ontario (October 2010) at 38. Additionally, I have illustrated the main challenges towards valid and applicable ADs in ch 4, particularly on the grounds of mental incapacity.

[103] Ibid, at 42.

people in their decision-making rather than purely applying the non-interference model is relevant to ADs. A person can refuse consent to the treatment offered in a contemporaneous treatment, where the decision can be reconfirmed or clarified. This ‘privilege’ is not accorded to an AD because the nature of ADs is such that it is to be implemented at a future time by a third party, in most cases, a doctor, because the person who makes the AD can no longer express the refusal. ADs present a range of variations from the time they were made to the time they were sought to be implemented. Such variations thus require a different layer of consideration from contemporaneous refusals. A non-interference type of autonomy is inadequate to assist people in directing their minds to the possibilities of future variations and to take into account such changes in their ADs.

Ideas about doctor-patient partnership model or shared decision-making type of decision-making[104] though helpful, were unclear as to how this can particularly enable or enhance a patient’s autonomy in medical decision-making. Recognising a doctor’s professional duty towards a patient could entail including other ethical principles to operate, such as beneficence, non-maleficence, care and justice. While a doctor has a professional role in medical decision-making, it is important to understand to what extent these roles can help or hinder patients in achieving their autonomy.

The current legally accepted understanding of autonomy is one that emphasises decision-making without interference from the others, unless the person consents to their involvement. Theoretically, if the non-interference approach is adopted in ADs, a person can refuse treatment without necessarily being advised or informed. Even if the decision is perceived as irrational, against his or her best interests, the decision should not be interfered with because the decision belongs to the person. The AD cases considered earlier revealed a different picture. For the most part, the ADs were not upheld often because the courts could not be sure that the ADs represented the patients’ autonomous wishes when it was sought to be implemented. The shift towards a patient-centric approach meant that the meaning of autonomy has to take a new form for the relationship to progress, especially in the context of ADs.

Having due regard to the special nature of ADs, autonomy should be conceptualised as including empowerment. According to the online Merriam Webster dictionary, empower means “to give official authority or legal power” or in the sense to enable, “to promote the self actualisation or influence of…”[105] Similarly, the Oxford English Dictionary defines empowerment as to “give (someone) the authority or power to do something” or “make (someone) stronger and more confident, especially in controlling their life and claiming their rights.”[106] Both suggested a more active role for the individual. The model of autonomy that I am endorsing is a more active, enabling one, concerned also with assisting them to develop capacities needed to make properly autonomous decisions. In addition, support which helps

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[104] For example see Vikki A Entwistle and Ian S Watt “Patient involvement in treatment decision-making: The case for a broader conceptual framework” (2006) 63 *Patient Education and Counseling* 268 at 270.

[105] http://www.merriam-webster.com/dictionary/empower.

[106] http://www.oxforddictionaries.com/definition/english/empower.

decision-making can also be used to strengthen ADs, by anticipating the sorts of challenges that they might face and taking proactive steps to avoid them, for example, the assessment of mental capacity.

Empowerment originated from "the social action ideology of the 1960s and the self help perspectives of the 1970s"[107] signifying a sense of "mutual support, coping skills, support system."[108] This concept can also be attributed historically to the period of time where people are being oppressed but needed to escape such oppressions through empowerment, for example, in concepts involving critical social theories, liberation of black people and recognition of homosexuality and women suffragette movements.[109] It can also encompass supporting people who are disadvantaged.[110]

Empowerment recognises the importance of human dignity. It also realised an individual's ability to decide.[111] Written from a nursing perspective, Gibson identified empowerment as "a process of helping people to assert control over the factors which affect their lives."[112] As it is a process this naturally involves "both the individual responsibility in healthcare and the broader institutional, organisational or societal responsibilities in enabling people to assume responsibility for their own health."[113] This connotes a positive action that enhances an individual's strengths and abilities. Measures to enhance such abilities can involve helping a patient "develop the knowledge, skills, attitudes, and degree of self-awareness necessary to effectively assume responsibility for their health-related decisions."[114] This means that measures or interventions that are carried out are for the purpose of enabling the person to be the decision-maker. The outcome then would be one where the person possesses an "enhanced sense of self-efficacy…as a result of the process."[115] From

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[107] Cheryl H Gibson "A concept analysis of empowerment" (1991) 16 Journal of Advanced Nursing 354 at 354, 355.

[108] Ibid.

[109] Inger Holmstrom and Marta Roing "The relation between patient-centeredness and patient empowerment: A discussion on concepts" (2010) 79 Patient Education and Counseling 167.

[110] Robyn Ouschan, Jillian C Sweeney and Lester W Johnson "Dimensions of Patient Empowerment" (2000) 18(1–2) Health Marketing Quarterly 99 at 102.

[111] Catherine Feste and Robert M Anderson "Empowerment: from philosophy to practice" (1995) 26 Patient Education and Counseling 139.

[112] Cheryl H Gibson "A concept analysis of empowerment" (1991) 16 Journal of Advanced Nursing 354. See also Christine M Rodwell "An analysis of the concept of empowerment" (1996) 23 Journal of Advanced Nursing 305; Judi Chamberlin and Aart H Schene "A working definition of empowerment" (1997) 20(4) Psychiatric Rehabilitation Journal 43; Stewart Piper "Patient empowerment: Emancipatory or technological practice?" (2010) 79 Patient Education and Counseling 173 at 174.

[113] Cheryl H Gibson "A concept analysis of empowerment" (1991) 16 Journal of Advanced Nursing 354.

[114] Catherine Feste and Robert M Anderson "Empowerment: from philosophy to practice" (1995) 26 Patient Education and Counseling 139.

[115] Robert M Anderson and Martha M Funnell "Patient empowerment: Myths and misconceptions" (2010) 79 Patient Education and Counseling 277 at 278.

a psychiatric rehabilitation perspective, Chamberlin and Schene identified empowerment as possessing the following attributes[116]:

Having decision-making power.
Having access to information and resources.
Having a range of options from which to make choices (not just yes/no, either/or).
Assertiveness.
A feeling that the individual can make a difference (being hopeful).
Learning to think critically; unlearning the conditioning; seeing things differently: e.g.,

(a) Learning to redefine who we are (speaking in our own voice).
(b) Learning to redefine what we can do.
(c) Learning to redefine our relationships to institutionalized power.

These are not the only features of patient empowerment. However these qualities highlight some of the possibilities for achieving patient empowerment, which can be modified to suit the purpose of the context. The bottom line is recognising the individual as the decision-maker capable of exercising an autonomous decision using support along the way. Grant Gillett's conception of autonomy as life skills reasonably inferred a notion of empowerment, in terms of equipping people who are disadvantaged with life skills so that they can make decisions again.[117] These life skills are drawn from learning from the others and participating in life experiences.[118]

The concept of patient empowerment is widely practiced in many areas, such as nursing,[119] mental health,[120] psychology and other specific areas of healthcare.[121] It is broad enough to include empowering patients who have specific learning abilities,[122] patients in clinical consultation through enhanced level of participation,[123] medical consultation[124] or having support persons in the doctor-patient communication. In many situations, empowerment is often associated with the provision

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[116] Judi Chamberlin and Aart H Schene "A working definition of empowerment" (1997) 20(4) Psychiatric Rehabilitation Journal 43; Stewart Piper "Patient empowerment: Emancipatory or technological practice?" (2010) 79 Patient Education and Counseling 173 at 174.

[117] Grant Gillett "How do I learn to be me again? Autonomy, life skills and identity" in L Radoilska (ed) Autonomy and Mental Disorder (Oxford University Press, Oxford, 2012) at 233.

[118] Ibid, at 235.

[119] Stewart Piper "Patient empowerment: Emancipatory or technological practice?" (2010) 79 Patient Education and Counseling 173.

[120] Judi Chamberlin and Aart H Schene "A working definition of empowerment" (1997) 20(4) Psychiatric Rehabilitation Journal 43.

[121] For example, in care of diabetic patients: Robert M Anderson and Martha M Funnell "Patient empowerment: Myths and misconceptions" (2010) 79 Patient Education and Counseling 277.

[122] Lisa N Rossignol and Michael K Paasche-Orlow "Empowering Patients Who Have Specific Learning Disabilities" (2013) 310 (14) JAMA 1445.

[123] S McCann and J Weinmanb "Empowering the patient in the consultation: a pilot study" (1996) 27 Patient Education and Counseling 227.

[124] Robyn Ouschan, Jillian C Sweeney and Lester W Johnson "Dimensions of Patient Empowerment" (2000) 18(1–2) Health Marketing Quarterly 99.

of information to patients, either in consultation or pharmaceutical contexts.[125] Empowerment focuses on the patient. It respects patients as the ultimate decision-maker and the support rendered to enable the patient to realise this autonomy. In a sense, empowering the patient in areas where the patient needs, respecting their preferences, emotional support, involving family and friends. It also recognises that, for example in a care giving situation, the caregiver relinquishes the "need to control the patient and determine what may be best for patients."[126] Consequently, this precludes a best interest approach as the first instance for medical decision-making when the patient becomes incapacitated.

Dunst and Trivette powerfully captured the operation and effects of the empowerment experience in respect of facilitating an individual achieve autonomy[127]:

> An empowerment perspective of helping relationships considers help giving effective when it provides help receivers opportunities to strengthen and develop their abilities, leading to a sense of control with regard both to solutions to problems and resolutions of concerns in a way that "not only sustains a person but also eventually makes the person self-sustaining.

Empowerment is particularly suited for ADs, as it recognises both the limitations and strengths of an individual to make decisions. It is pre-emptive in the sense that it provides a clear 'behind-the-scenes' process of what happens in the decision-making course. The non-interference conception of autonomy does not always enhance a person's autonomy and is insufficient to capture the nuances of ADs. This is especially important and valuable because the courts, as demonstrated previously tried to build a picture of what went on when the patient made the AD. The patient can now no longer speak for himself. Evidence of an empowered patient helps towards realising those wishes. Such evidence can occur in the form of, for example, a doctor's report when he assessed the patient's mental capacity, the circumstances and background of the patient, among others. Providing such evidence helps strengthens the person's wishes and represents a more authentic, genuine autonomous decision. It is a substantive, meaningful type of autonomy which affects the process and the outcome of the decision-making. The legal concept of mental capacity meanwhile appears to contribute to the practical limitations of deciding whether a person is competent or not when it comes to implementing AD.

In the context of an AD, empowerment acknowledges the vulnerability of the patients and their need to be assisted and supported in medical decision-making. Vulnerabilities may occur in the form of physical disabilities or where the person realises that he needs help or that his current situation was inadequate to allow him to make a decision. The person may request help in making decisions through soliciting further information, seeking second opinions or having third parties to deliberate on any matter. Empowerment is thus important in both of the contexts of contemporaneous and anticipatory decisions. The type and timing of empowerment

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[125] Parisa Aslani "Patient empowerment and informed decision-making" 2013 (21) International Journal of Pharmacy Practice 347.

[126] Ibid, at 170.

[127] Carl J Dunst and Carol M Trivette "Empowerment, effective help giving practices and family-centered care" (July–August 1996) 22(4) Pediatric Nursing 334.

given to the person varies in different context. With ADs, it may have to include, for example, a warning for the patient that certain unforeseen events may occur that the patient cannot explicitly provide for.

Empowerment is an inclusive concept that applies to a range of contexts. Medical decision-making is a good example of a situation where there exist many permutations that require support to empower the person with capacity in expressing a preference.[128] The current literatures support the idea of empowering people with capacity in various medical contexts in making medical decisions; which suggest that the concept is not applied exclusively to people with intellectual or physical disability.[129] This is a broader framework to become applicable to people who are presumably competent, because empowerment does not preclude people with either physical or mental disabilities. In order for empowerment to operate in AD, several assumptions must be assumed. It must be assumed that the patient may reject the information and refuse to be empowered, because the ultimate decision-making lies in their hands. On the other hand, doctors are in the position of power and thus poised to disseminate and clarify information, as well as assist patients in making their ADs. Not only that, they can, when it comes to applying the AD know what the patient

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[128] An example of a form of patient empowerment in medical decision-making in the context of preventing medical errors is patient advocacy groups. These groups work with patients in educating them on various health care issues and raising awareness about preventing medical errors with healthcare providers. See Clara Aw´e and Swu-Jane Lin “A Patient Empowerment Model to Prevent Medication Errors” (2003) 27(6) Journal of Medical Systems 503 at 514, 515. A patient advocate is also a feature in the New Zealand healthcare system.

[129] Heather K Spence Laschinger and others “Towards a comprehensive theory of nurse/patient empowerment: applying Kanter’s empowerment theory to patient care” (2010) 18 Journal of Nursing Management 4; Penny Powers “Empowerment as Treatment and the Role of Health Professionals” (2003) 26 Advances in Nursing Science 227; Mushin Lee and Joon Koh “Is empowerment really a new concept?” (2001) 12 The International Journal of Human Resource Management 684; N J Fox, K J Ward and A J O’Rourke “The ‘expert patient’: empowerment or medical dominance? The case of weight loss, pharmaceutical drugs and the Internet” (2005) 60 Social Science & Medicine 1299; Patricia M Wilson, Sally Kendall and Fiona Brooks “The Expert Patients Programme: a paradox of patient empowerment and medical dominance” (2007) 15 Health and Social Care in the Community 426; Flis Henwood, Sally Wyatt, Angie Hart and Julie Smith “‘Ignorance is bliss sometimes’: constraints on the emergence of the ‘informed patient’ in the changing landscapes of health information” (2003) 25(6) Sociology of Health & Illness 589; Peter Salmon and George M Hall “Patient empowerment and control: a psychological discourse in the service of medicine” (2003) 57 Social Science & Medicine 1969; Isabelle Aujoulat, Renzo Marcolongo, Leopoldo Bonadiman and Alain Deccache “Reconsidering patient empowerment in chronic illness: A critique of models of self-efficacy and bodily control” (2008) 66 Social Science & Medicine 1228; Clara Aw´e and Swu-Jane Lin “A Patient Empowerment Model to Prevent Medication Errors” (2003) 27(6) Journal of Medical Systems 503; James E Rohrer and others “Patient-centredness, self-rated health, and patient empowerment: should providers spend more time communicating with their patients?” (2008) 14 Journal of Evaluation in Clinical Practice 548; Isabelle Aujoulat, William d’Hoore and Alain Deccache “Patient empowerment in theory and practice: Polysemy or cacophony?” (2007) 66 Patient Education and Counseling 13; Nancy Tomes “Patient empowerment and the dilemmas of late-modern medicalisation” (2007) 369 Lancet 698; Robert M Anderson “Patient Empowerment and the Traditional Medical Model: A case of irreconcilable differences?” (1995) 18(3) Diabetes Care 412; Kathleen Johnston Roberts “Patient empowerment in the United States: a critical commentary (1999) 2 Health Expectations 82.

would want because of the benefit of having discussing it with them prior. The focus is then on the patient where such patient becomes empowered through a process of interactions with a doctor.[130] In reality, people need support in some form, but requesting support does not mean a person becomes less empowered. Information is not merely treatment information, information can encompass knowing the characteristics of AD and highlighting this understanding to the patient so that they know what to expect from an AD and how it can best be used to promote their autonomy or in exercising their autonomy. This connotes that doctors or people assuming care for the person should recognise the person's right to decide and to plan ahead and understand the patient's point of view. Patients wishing to make ADs can decide at their own pace and time, through collaborative efforts which connotes a more active, positive action in ensuring that they are being in the right condition to make a decision.

4.4 Conclusion

Autonomy is recognised as the pre-eminent value in doctor-patient relations, in which, at least theoretically, the patient is viewed as a freely choosing consumer in a healthcare supermarket. Any healthcare providers is free to serve the consumer and the consumer can certainly decline any unwanted treatment, for almost any reason the consumer likes—even one that is completely irrational, provided that the consumer is competent to choose. It would be premature to hold that the assumption that all other ethical considerations are only considered in the absence of an autonomous choice is translated into practice. The reality is that a person's autonomy is open to scrutiny when it comes to refusing life saving treatments.

Reframing autonomy as empowerment is valuable and adequate in the context of ADs because of the differences between a contemporaneous refusal and an AD. These differences marked different outcomes for the binding status of the decision. Consistent with the spirit of autonomy as empowerment, support is an essential feature to enable this concept. This therefore recognised that doctors and families have some roles to play, either in the form of the doctor's expertise or families who are informed about the patients' decision who can verify the decisions when it comes to applying the AD. An AD represents a conscious effort to preserve what is important to the individual. Autonomy in the ordinary, non-interference understanding seems to no longer hold true in light of the challenges for achieving autonomy in ADs and its inadequacy in an AD context. Fenella Rouse accurately noted that "the need

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[130] Inger Holmstrom and Marta Roing "The relation between patient-centeredness and patient empowerment: A discussion on concepts" (2010) 79 Patient Education and Counseling 167 at 168.

for informed refusal…springs instead from a societal interest in enabling a person to pursue his or her own particular plan of life and from our contemporary health care system in which we are forced to accept the idea that treatment is sometimes provided when the patient would refuse it. What we are doing when we promote the idea of informed choice in medical treatment is striving to create a world in which the individual is allowed to act on the knowledge of what, for him or her, creates individual happiness."[131] The SDM approach which embodies the qualities of empowerment thus supports people in achieving autonomy.

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[131] Fenella Rouse "Does Autonomy Require Informed and Specific Refusal of Life-Sustaining Medical Treatment?" (1989–1990) 5 Issues L & Med 321 at 324, 325. See also Gerard V Bradley "Does Autonomy Require Informed and Specific Refusal of Life-Sustaining Medical Treatment?" (1989–1990) 5 Issues L & Med 301 at 303 where the author, using the example of state governance to its citizens, that "[I]t is neither theoretically nor practically true that where the state is held at bay, citizen behavior is therefore a matter of individual autonomy."

Chapter 5
A Supported Decision-Making Model for Advance Directives

5.1 Introduction

The SDM approach empowers patients and strengthens the person's AD. It is particularly valuable at the time when the patients are formulating and setting down their wishes. Generally, SDM employed at the time the AD was made could address the concerns raised about the patient's mental capacity and understanding of the consequences of the treatment refusal, as well as future changes that would impact upon the AD.[1] In the process of creating an AD, a variety of expertise drawn from a range of people can assist the person concerned. This would vary depending on the particular needs of the circumstances.[2] As an illustration, a doctor may fulfil the role of explaining the diagnosis, prognosis and treatment options, akin to a contemporaneous setting where there are no reasons to doubt the person's mental capacity or understanding of treatment. Involving a doctor in this process could be helpful because a doctor is in a position to explain to the patient that circumstances may change when the AD is sought to be implemented, or having the benefit of creating an AD that avoid overly vague or general expressions that

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[1] For example, Phillipa Malpas in Phillipa J Malpas "Advance directives and older people: ethical challenges in the promotion of advance directives in New Zealand" (2011) 37 J Med Ethics 285 at 287 suggested that in the context of a consultation between a doctor and a patient regarding an AD, discussions could include possible future scenarios and probable medical treatments, such as treatment outcomes, consequent burdens and benefits. Malpas also recommended that a more personal topic concerning the patient's desire for control at the end-of-life could be broached at this stage.

[2] Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell "Supported Decision-Making: A Viable Alternative to Guardianship?" (2013) 117 Penn State Law Review 1111 at 1123. Kohn, Blumenthal and Campbell suggested that "SDM relationships may also occur in the context of 'circle of support' or a 'microboard.' Such circle of support consists of "a group of people, typically family members and friends, who meet regularly with a person with a disability to help that person formulate and realize his or her hopes or desires."

H. Y. Chan, *Advance Directives: Rethinking Regulation, Autonomy & Healthcare Decision-Making*, International Library of Ethics, Law, and the New Medicine 76,
https://doi.org/10.1007/978-3-030-00976-2_5

would be difficult to interpret. Drawing a parallel example from a doctor's viewpoint regarding patients' dying and a doctor's role, Atul Gawande, a prominent doctor and writer accurately observed that people need the expertise of doctors and nurses to discuss the realities of dying in preparing them for the eventuality.[3]

An example where SDM may have started gaining some attention in practice is in a situation where people are recommended to inquire about support available from healthcare professionals in making ADs, where such services are offered by healthcare professional's organizations.[4] It is reasonable to suggest that healthcare professionals identify the potential difficulties faced by people in making choices about future treatment decisions, taking into account any grave repercussions arising from such decisions. Consequently, these individuals require support in the process of making ADs. More support is anticipated for a situation where the individual is borderline competent and wishing to make an AD. In such instances, doctors, psychiatrists, psychologists, social or mental health workers would be enlisted to provide the support. This would also include the involvement of families or lawyers. In respect of families, they may fulfill the role of explaining information conveyed to the person in an accessible manner, or simply, to provide emotional support.[5]

As identified in Chap. 4 previously, there is a spectrum of decision-making between contemporaneous refusals and ADs covering a range of ADs which may or may not be legally binding, and made by individuals at various stages in life or medical condition. The cases in Chap. 3 illustrated the distinctions between these spectrums of decision-making where the presence or lack of opportunities to speak to the patients affect the outcome of the ADs. For ease of reference and discussion

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[3] Atul Gawande "Letting Go: What should medicine do when it can't save your life?" (2 August 2010). http://www.newyorker.com/magazine/2010/08/02/letting-go-2. Accessed 10 July 2016.

[4] Some examples include Royal Australasian College of Physicians RACP Submission: Draft Advance Care Directive DIY Kit (March 2014) at 2 where the RACP favoured the involvement of doctors and carers in helping patients and families understand and complete AD forms. Other healthcare organisations recommending doctors' involvement include New Zealand Health and Disability Commissioner "Advance Directives in Mental Health Care and Treatment". http://www.hdc.org.nz/publications/resources-to-order/leaflets-and-posters-for-download/advance-directives-in-mental-health-care-and-treatment-(leaflet). Accessed 9 June 2016; American Medical Association "Advance Directives". https://www.ama-assn.org/delivering-care/advance-directives. Accessed 9 November 2017; ABA Commission on Law and Aging "Myths and Facts about Health Care Advance Directives". http://www.americanbar.org/content/dam/aba/uncategorized/2011/2011_aging_bk_myths_factshcad.authcheckdam.pdf. Accessed 8 June 2016; NZMA Member Advisory Service Information Sheet "Advance directive information and sample form". https://www.nzma.org.nz/__data/assets/pdf_file/0018/77040/Advance-Directive_sample-forms.pdf. Accessed 8 June 2017; B Pace "Decisions about End-of-Life Care" (2000) 284 JAMA 2550; B Pace "Advance Directives for End-of-Life Medical Decisions" (2000) 283 JAMA 1518.

[5] Note that while some people would favour a greater role for families in supporting them during the discussion process, the presence of families may present some dangers in the sense that the patient may be reluctant to express their decisions genuinely for personal reasons. See also J Craigie "A Fine Balance: Reconsidering Patient Autonomy in Light of the UN Convention On The Rights Of Persons With Disabilities" (2015) 29 Bioethics 398 at 402, 403. In this article, Craigie identified the challenge of effectively exercising autonomy in the decision-making process while receiving support and guarding against attempts at potential influences that might undermine the freedom to decide.

of the operation of SDM, I have classified the ADs discussed previously under three categories:

(a) The first type is made by a person who is mentally competent but is either suffering from physical disabilities, terminal illness or undergoing imminent medical procedures. An AD under this category includes patients such as AK, XB (AK-type cases), Mr D and Andrew. Their ADs can be broadly classified as A-type ADs.

(b) The next type is made by persons who are healthy but make ADs in case they become incompetent in the future, such as Benjamin or people similar to Benjamin, such as KH. It can also include ADs made by Jehovah's Witnesses or where there are suspicions of residual beliefs. Examples include AE and Miss T. This type of AD is known as B-type ADs.

(c) The third type of ADs is made by patients whose mental capacity is at issue, such as Miss E (anorexic) and Ms T (bloodletting patient); This third type falls under T-type ADs where the issue of AD arose at the time of implementation with no prior opportunity to speak to the patients.

5.1.1 A-Type ADs

In respect of A-type ADs, SDM performs its traditional role of assisting the person to communicate and determine his wishes. For example, in AK, he was physically impaired because of the neurodegenerative disease and was locked-in; resulting in his inability to move his body except for his limited eye movement. He communicated through a communication board, a painstaking procedure, which was then recorded by his doctor. Throughout the process of communicating and recording his AD, the doctor was able to observe and assess him. SDM helped AK to communicate with his doctor in expressing his decision to cease ventilation two weeks after he lost the ability to communicate. Although the court was concerned with the possibility of change of mind, his refusal was confirmed by his doctor and the court appointed lawyer through the same communication method. AK knew that he could change his mind about his wishes. He had made the decision to refuse ventilation after he had fully understood the nature of his illness, the prognoses and treatment options. This information was provided to him, together with updated information relevant to his treatment. Independent specialists arranged to speak to him were satisfied that AK knew what he was refusing. The court was satisfied that AK had competently, voluntarily and with full understanding of the nature and consequences of the refusal made his AD. His AD was upheld.

5.1.2 B-Type ADs

The problems that occurred with B-type ADs arose when they were sought to be implemented. The AD was often made some time before the patient became unwell. There were questions about the validity, applicability and potential subsequent changes that may occur. The B-type ADs were not binding because it was not known whether the person who made the AD was mentally competent at that time it was written, or whether the person was acting voluntarily and with an understanding of the nature and consequences of the refusal. There was also the problem of applying the AD. If the contents were vague or imprecise, or fell outside the scope of the AD, the AD would be inapplicable. SDM could have addressed the weakness at the time it was made in respect of making a valid AD. The main thing is advising the person about what the person is refusing. For example, in Benjamin's case, although it was a specific refusal, a doctor could have explained to him that it was a standard life saving treatment and what would be the consequences of refusing such treatment. The discussion could also reveal his reasons for refusing such treatment. Without the benefit of this discussion, Benjamin might not be aware of the risks and consequences of what he was refusing. It could also clarify whether Benjamin would still refuse at all cost or whether he would be willing to accept transfusion under specific conditions or other alternatives.

Another aspect is addressing the subsequent changes for B-type ADs. SDM may not be able to confirm whether and when Benjamin had changed his mind, but at the stage of making the AD, the possibility that changes will occur can be highlighted to him and an alternative can be provided for in his AD. It is also feasible then to explore the possibility of Benjamin assuming the risks of refusing where the circumstances have changed. He could also provide for the frequency of reviewing his ADs during consultations with his doctors and the people who would need to be informed of such periodic reviews. Having another person who knows about his AD can help towards either clarifying his wishes in the AD or identifying the substitute decision maker. These are some of the questions that a doctor may ask for B-type ADs.

5.1.3 T-Type ADs

T-type ADs present more complex problems, both at the validity and application stage. As the cases have shown, there is an association between the mental capacity and the nature of the refusal. For example, in *NHS Trust v T* the court seemed to suggest that Miss T was not mentally competent because her reason for refusing transfusion was because she viewed her blood as evil. There is the difficulty of ascertaining whether a person is mentally competent or otherwise. Assessing capacity may involve psychiatrists, psychologists, or other specialist according to the nature of the person's refusal. Even if no issues were raised as to the validity of the AD, the courts would still want proof of validity of the AD, especially proof of capacity. As such, SDM may have some limited application in this instance.

The following section revisits some of the problematic cases examined in Chap. 3 and considers how SDM earlier in the process may have helped to avoid the problems that arose.

5.2 Application in ADs Cases

5.2.1 A-Type AD: Conventional SDM Application

5.2.1.1 AK and XB: Patients with Physical Disabilities

A type of patient under this category is mentally competent at the time of making the AD, but due to impairments arising from illness requires assistance to communicate his wishes. Such patients would benefit from SDM the most because SDM can perform its more conventional role in assisting patients whose illnesses and disabilities have limited their ability in expressing their wishes and writing their ADs. AK and XB are good examples of patients who, left on their own, would not be able to express their wishes, but who could potentially attain such ability with the right sort of support. Both AK and XB suffered from motor neuron degenerative disease that left them physically impaired although mentally intact and competent. Their illnesses were specific and their ADS were made in anticipation of the known progression of their illness. It was clear that they had exercised their autonomous choices despite their physical disabilities. Their refusals were communicated to the doctors via painstaking movements of their eyes and then recorded in writing by their doctors. The courts recognised the laborious process under which AK and XB had expressed their wishes and the record evidencing their wishes and specialists' findings who were involved in assessing them. The decision-making process occurred over a considerable period of time with sufficient opportunities for the doctors to communicate with them and confirm their refusals. The courts in both cases were satisfied that their ADs were made while they were mentally competent, had acted voluntarily and understood the nature and consequences of the refusal and their ADs were upheld accordingly.

AK's case highlighted the importance of revalidating an AD. Revalidation is necessary in an AD because there is no opportunity to review the decision once the person becomes incompetent. It is important as it provides an opportunity to reflect on the preferences, to revise any decisions or as an instrument to consult doctors about any concerns regarding treatment options. We know that AK's decision to cease ventilation was revalidated several times as the changes in his circumstances occurred, when he became aware that he would subsequently become unable to communicate. The court looked into how long ago, and on what basis and with what information, the AD was made. Having satisfactorily found that AK's decision was recently made with the fullest possible knowledge of imminent reality, AK had demonstrated that the AD represented his genuine wishes, which was accepted as binding.

5.2.1.2 Andrew: Patient Undergoing Immediate Medical Procedure

Andrew, the hypothetical character discussed in Chap. 4, is another A-type AD, but in this case he had no physical disabilities that made communication difficult. Andrew was preparing for an imminent surgical procedure, fully conscious and able to participate in the SDM process. His AD was made in anticipation of future incapacity by specifying the type of treatment he would like to refuse. In Andrew's case, he was about to undergo angioplasty and had refused open heart surgery if complications arose. His contemporaneous refusal became a valid AD as soon as he was anaesthetised. Andrew had been assessed by his surgeon prior to the surgery and was found to be competent, had acted voluntarily and had understood the nature and consequences of the refusal. In addition, his doctor had fully discussed the options and consequences of his refusal and it was clear what the doctor would do in the event the risks materialised. Where Andrew had a support person with him when the discussion took place, the person would be able to confirm Andrew's refusal. In any event, SDM would have assisted him in making a clear and informed statement of his wishes and when the risk eventuated; his AD would come into effect.

5.2.1.3 Mr D: Patient with Terminal Illness

The English case of Mr D illustrated one way where SDM could help him while he was making his AD. In that case, Mr D was a patient in a permanent vegetative state by the time his application was brought to the court. He had made an AD refusing life prolonging medical treatment in anticipation of surgery. Complications arose during the surgical procedure causing him to lapse into a permanent vegetative state. His AD was not acted upon on the ground of non-compliance with the formal requirements of sections 25(5) and 25(6) of the MCA. Mr D's refusal was a refusal for life sustaining treatment, which under the MCA has to be in writing, verified by him that it should apply even if life is at risk, signed and witnessed. Although his AD was written and signed, it was not verified and witnessed. In this context, Mr D would benefit from the support of a legal professional among the range of professionals and support person in the decision-making process. Had Mr D made the AD with assistance from a legal professional, there would be a greater likelihood that the withdrawal of treatment would be in accordance with his AD. SDM in the form of legal advice would enable him to be aware of the necessity of complying with the formalities under the MCA for refusal of life sustaining treatment. In the alternative, if Mr D had expressed his wishes to his family members as well as his surgeon or doctor the latter could assist him by alerting him to the forms when he talked about making one. The doctor then could point him in the right direction by preparing the forms. As it was a refusal of life sustaining treatment, which under the MCA has specific formalities, Mr D could have been assisted with the support by having that explained to him and then perhaps it can then help him comply with the provisions of the MCA. Although the MCA does not specifically require people to seek legal advice in formalising an AD, compliance with the formalities is essential. Mr D had not complied with the formal requirements and hence his AD was invalid. His wishes were nonetheless respected, because the medical opinion was that the withdrawal of treatment was in his best interests.

5.2.2 B-Type ADs: Modification of SDM Approach

The B-type AD illustrates ADs made by people who are well, and who anticipated future incapacity, as exemplified by Benjamin, the hypothetical character discussed in the preceding chapter and Ms KH, the patient whose feeding tube fell off, as discussed in Chap. 3.

5.2.2.1 Benjamin

Benjamin was a patient who had adamantly refused to accept transfusion due to a personal aversion to blood. When he was rushed to the hospital following an accident at a car racing event, his doctor found his AD refusing blood transfusion. In that scenario, there were challenges to implementing his AD due to several weaknesses: his refusal to accept a blood transfusion was unclear as to its applicability due to the vague expression that he "would not want any blood transfusion under any circumstances." It was unknown whether he had intended his AD to apply even if his life was at risk, given that his refusal related to standard life saving procedures. There would be questions about his mental capacity and genuineness in refusing such transfusions. Nor was it known if he understood what he had refused. Now that Benjamin has become unconscious it would not be possible to confirm with him if his AD still represented his wishes. We consider the validity and applicability aspects of his AD and the SDM application in assisting him.

Validity

Benjamin suffered from a concussion prior to making the AD. However, upon examination by his doctor, his headache was not a result of the concussion. The effect of concussion on a person's brain may materialise at different times. It could never materialise or it might have little to considerable impact, depending on the person's health. This action itself could not certainly rule out that Benjamin was competent when he made the AD. Although it could not be said that it was a mental capacity assessment for the purpose of making an AD, it indicated that there should not be any doubt to his mental capacity, assuming that the presumption of capacity applies. However, as demonstrated by the case law, proof of capacity is often in fact required, so SDM could possibly help him here where a capacity assessment is undertaken for the purpose of making an AD.

There was no evidence that the doctor knew whether Benjamin had genuinely refused blood transfusion. Benjamin's refusal was based on a personal aversion to blood and it was possible that his action had been wholly based on inaccurate information about transfusion related deaths of his close relatives. Such information may have skewed his perception of the risks involved in blood transfusion. SDM may help where there is an opportunity to speak to Benjamin to clarify the misunderstanding of the information he had when he made the AD. Similarly, the doctor would be able to know what information Benjamin had obtained when making the AD.

One way SDM could help him at the time he made the AD was through consultation with healthcare professionals regarding further information about treatment refusal specific to blood transfusion. A discussion with a doctor might have given him a better sense of perspective, or at the very least, clarified his aversion that could arise from a misunderstanding about risks involving blood transfusion. The doctor or other healthcare professionals would be able to explain the much reduced risks from blood transfusion or it would uncover any details about any peculiar health characteristics affecting Benjamin that would make him more prone to risks of blood transfusion. Even if he did not waver from his aversion affecting his refusal in the end, he would know what a refusal of blood transfusion entailed. In respect of clarifying the information about making ADs, SDM could have helped Benjamin understand the legal effect of making an AD.

Application

Benjamin's AD refused blood transfusion "under any circumstances". But the doctor did not know whether he had actually intended his AD to apply in all circumstances, given blood transfusion is a standard life saving procedure. SDM would be unable to clarify in what circumstances he had intended the AD to apply, given that he was now unconscious. Nevertheless if he had the benefit of medical explanation above, it would be clearer as to his intention regarding the AD. In the alternative, had Benjamin involved a friend or family as a support person in the process of making his AD, this person could have played a role in interpreting his wishes.

The doctor would not know if any changes had occurred in Benjamin's circumstances since he made the AD or whether he had taken into account the effect of any changes in personal circumstances that would make him rethink his refusal. It is possible that his parents would know, although doubt remains as to whether Benjamin has definitely changed his mind in view of the changes in his personal circumstances.

However, the SDM process could have helped him institute some measures which would be helpful at the time his AD came to be implemented. For instance, Benjamin would benefit from a doctor's emphasis of the importance of updating and revalidating his AD to accommodate the possibility of subsequent changes. Benjamin would at least be aware of the difficulties that could arise should he change his mind about refusing blood transfusion without amending his AD. Another option is the presence of a support person who can clarify or interpret his wishes at the time of implementing his AD. The support person is one who is privy to his preferences at the time he made the AD and who is able to communicate the decision making process in case of doubt.

5.2.2.2 KH

KH is another example of a B-type AD. KH was the patient whose feeding tube had fallen out. The hospital had wanted to reinsert the feeding tube but her family opposed it arising from statements that KH had previously expressed that she would not want to live in her current circumstances. The court ordered the reinsertion of the feeding tube because there was no clearly expressed AD refusing treatment in her current circumstances. Her previous wishes were expressed in a conversation many years ago prior to her becoming incompetent but were not addressed to withdrawing feeding. The court did not think that she had appreciated the nature and consequences of the refusal, as a person would if the person had discussed the refusal with a healthcare professional. As a whole, the court was unconvinced that KH knew what she was refusing.

Validity

KH had the knowledge about her multiple sclerosis diagnosis from her doctor, but there was uncertainty as to the type of information she had regarding the development of the illness. Equally, there was a lack of certainty about the information she had concerning treatment care and options necessary to help her achieve her wishes of not being a burden on her family in view of the prognosis. Assuming that KH did not possess information about the progression of her illness, SDM could help her by having medical experts in multiple sclerosis inform her about the nature of the illness and what it entailed to allow her to plan for her future care. Additionally, when such consultations take place, she could understand and appreciate the relevant stages she was at since her first diagnosis and the amount of time left before she became incapacitated. She would thus have a clearer and improved understanding of her preferences; what is acceptable to her and her initial thoughts on what constitutes a burden to her family would be.

Another aspect of assistance for KH is an understanding of the consequences of refusing food and water. It appears that the facts did not reveal that she had been aware of such information, although she alluded to wishing for the best quality of life. Thus, SDM here could help KH by keeping her informed about the effect of refusing food and water, as explained by a healthcare professional. This could be discussed when the diagnosis came to light, offering her information about alternative treatments or palliative options available to people suffering from similar illness. Such consultations would be comparable to a contemporaneous medical consultation. KH would be more likely to have made an AD that is clearly in anticipation of the deterioration arising from multiple sclerosis, rather than based on incomplete or incorrect assumptions.

In the case where her mental capacity was doubted (although it was unknown in this case), SDM could assist her by having trained professionals assess her mental capacity. On the other hand, where there is a lack of evidence that she possessed the requisite mental capacity, KH would have to rely on the presumption of capacity. Capacity, generally changes with time, and could vary according to a variety of tests used to measure such capacity. As long as KH can demonstrate that she had understood the nature of her illness and the type of treatment she would refuse and the consequences of such refusal, there should be less likelihood to doubt her understanding.

In respect of ascertaining her voluntariness in refusing treatment, SDM could help KH at the time she made the AD where the doctor would have the opportunity to detect any signs of undue influence when she expressed her refusal. Doctors or experienced nurses could identify such influences, providing the opportunity to eliminate such influences, taking her a step closer towards making a valid AD. In this sense, it would mean requiring KH to understand that she would still voluntarily assume the risk of refusing treatment.

Application

In KH's situation, while her medical diagnosis was clear, it was unknown whether there were any subsequent changes to her personal circumstances that would likely impact her decision. However, the evidence of her family and close friend seemed to suggest that KH would most likely maintain her refusal in her current circumstances. KH could, while she was competent, make a statement to the effect that her family's evidence would be preferred (although this would be open to whether it would be accepted), or to appoint them as attorneys under a power of attorney or as substitute decision maker. She could also nominate her close friend, or other family member as support person who would be able to confirm her wishes when he AD is sought to be applied. If KH's case were to occur in New Zealand, her family's view would be taken into account as her right as a healthcare consumer.[6]

KH's case raised the issue of oral AD. The Court took issue with the lack of, or absence of a clear AD but did not specifically point out that an AD should be in writing. Nor did the Court clarify that if her AD had been expressed in writing it would have helped her cause. AK's case showed that the evidence comprising of reports from his treating doctors, consultants and independent specialists were credible enough (in addition to his recorded AD) to make a case for his AD. It is thus highly possible that where such a record exists in KH's case, they would render some weight to KH's expressed wishes. It is not entirely clear if the Court would accept oral ADs, because under the common law an AD can be in both. Writing would prove

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[6] Right 7(4)(c) of the Code of Rights.

that the statement had been made at all, and presumably, that it had been intended to be taken seriously. The risk is that an oral AD is more difficult to prove, because it depends on others saying what the patient wanted.

Apart from writing, the cases considered thus far suggest that formalities such as witnessing and signing do not play a role in the Court's decision. Recall that Ms T's (the bloodletting patient) AD was signed and witnessed in the presence of a solicitor, accompanied by her doctor's letter. The Court seemed to be more concerned with the content of her refusal rather than the formalities. This was also the case with Miss T (Jehovah's Witness) whom the Court construed her act of signing the refusal form as one in form rather than in reality. In fact, Munby J in *HE v A Hospital NHS Trust & AE*[7] declared that "an advance directive does not need to be in writing and signed, nor need it be attested by witnesses."[8] However, this statement needs to be viewed in the light of explicit rules governing binding ADs, such as ADs refusing life sustaining where specific formalities apply in the MCA.

A further point to consider is the existing therapeutic relationship between a patient who made the AD and the doctors. AK was continuously treated by his doctors who naturally came to form a strong therapeutic relationship over the years. His doctors can confirm his wishes and understand him well enough to detect if he had decided under inappropriate influence. Over the years AK was able to appreciate and respond to the care given by the doctors. KH in contrast, although a long term resident at a nursing home was hospitalised thereafter for a shorter period of time. Even if she was conscious she could not recognise anyone and had been mentally incompetent for a long period of time.

5.2.2.3 AE

AE is an example of a B-type case where her AD refusing blood transfusion as a Jehovah's Witnesses was invalidated due to subsequent changes. AE was a Jehovah's Witness who had allegedly changed her religious belief resulting in doubts about her prior blood transfusion refusal. It illustrated a change of circumstance that resulted in a change of mind affecting the binding effect of her AD. In AE, conflicting claims by her parents regarding her engagement to a Muslim man and ceasing to be a Jehovah's Witness could not be established with certainty and there was no evidence that she had made any formal or clear statement to this effect. Undoubtedly, each has a vested interest in AE.

SDM in this context is concerned with whether and how it can help AE when the doctor sought to apply her AD. The role of SDM here involves bringing to the court's attention evidence of subsequent changes as presented by the families. The evidence could then confirm or negate AE's AD. The court will have to consider how much weight to attach to their claims about her change of mind. Although AE is

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[7] *HE v A Hospital NHS Trust & AE (by her litigation friend the Official Solicitor)* [2003] EWHC 1017 (Fam).

[8] Ibid, at [35].

already incompetent, there could be a way for SDM to navigate through the conflict of evidence between family members about the AD.

This case provides an opportunity to consider familial involvement in AD disputes concerning subsequent changes after the making of AD. Examples where families played confirmatory roles in the process of making ADs were XB and Mrs Malette. In XB's case, the evidence of his doctor and his family collected during the recording of XB's refusal had confirmed XB's intention in refusing ventilation. Similarly, Mrs Malette's daughter had confirmed to Dr Shulman that her mother had never ceased being a Jehovah's Witness. In both cases, the family was merely confirming that the patients had not changed their minds.

One option for SDM to apply is that, at the time the AD is made, the SDM process can involve the family members who would be assuming the responsibility of care of the patient when the patient becomes incapacitated. Disagreements can be set out and recorded. Where the patient elects to have family members, close friends or support persons present during these consultations, the doctor should record any evidence of people present and what each said. This is useful to indicate whether the patient was acting freely when consenting or refusing. Such record can serve as evidence verifying the patient's wishes. However, this option does not eliminate the possibility of the disagreements resurfacing in the future when the AD is sought to be implemented. The difference in those cases was that only one side of the family was involved when the AD was purportedly made.

Another option is for the patient to address this conflict by nominating a person (not necessarily a family member) as the reference point in the event of conflict in the future, preferably someone who does not have any vested interest in the person's AD at the time of making the AD. By taking this step, it potentially removes another obstacle in deciding how the conflict should be resolved. The patient can be supported to identify such suitable persons.

As we probe AE's situation, there were other opportunities for SDM when AE was making her AD. Her AD was made in the presence of Church Elders and her mother while living in a household believing in that faith. She should have been advised by a doctor at the time when she signed the AD about the nature and consequences of her refusal. She would then have had an opportunity to understand the implications of her decision. If she then remained committed to her decision, the doctor would have been able to verify that she understood the nature and consequences of her decision. The doctor could also highlight to AE the importance of changing her AD should she ever change her mind. Such situations, however, are still likely to be at least somewhat difficult. Religious beliefs and matters concerning spiritual faiths may not be easily separated from reason. A person can be mentally competent in all respects but when the mind is made up there can be no room to negotiate.

SDM can help AE when she had her consultation sessions with the doctor. Prior to her becoming incompetent, there was a missed opportunity to revalidate the refusal when the doctor saw AE during consultation. The court acknowledged that the longer the time since the AD was made, the more reason there was to scrutinise its continuing validity.[9] While AE anticipated that the AD was made with the view that it was to become applicable when she was undergoing surgery for her heart problem, there was no evidence that she had reviewed it since becoming engaged to her Muslim fiancé. AE could have revalidated her AD after her betrothal to reflect her more current wishes consistent with the changes in her personal life.

In the alternative, when AE was admitted to hospital prior to becoming ill, there was an opportunity to discuss the AD. AE's father alleged that AE had on two separate occasions admitted herself to hospital and had remained for two days, made no reference to the AD and the doctor had not enquired into it despite the note about her faith in her medical record. It is unknown whether there was an additional consultation after she was admitted to the hospital and whether the doctor had been alerted to such changes.

5.2.2.4 Re T

Miss T was the pregnant woman injured in a traffic accident who contracted pneumonia and had an emergency caesarean to deliver her child which was stillborn. She was incompetent at the time she expressed her refusal to receive blood transfusion. There were suspicions about her voluntariness and that she had been misinformed about the alternative blood products when she enquired about it. Although her medical record showed that she still possessed some residual belief as a Jehovah's Witness, her weakened state, together with her physical vulnerabilities had made her more susceptible to her mother's pressure.

What can be done here is to support T in expressing her wishes in a different environment. More specifically, the doctor could, when she first volunteered her refusal out of the blue, reconfirm her refusal and explain to her the gravity of her refusal. If the doctor suspected that it was because of her mother's pressure, her doctor could transfer her to another space or request that the mother leave the room. If she had insisted on her mother's presence then there was nothing to stop her from doing that, but the doctor could at least inform or warn her about the alternative blood products and the risks of refusing blood transfusion. However, no such action was taken at that time. The discussion between T and her mother occurred when no one else was present that the court had to draw inferences as to what was said. It would be impractical to have a mental capacity assessment when T's condition had deteriorated following her caesarean section operation, but there was an earlier time when she was still conscious when she first expressed her refusal that the doctor could assess her.

Another issue that the trial court dealt with was Miss T had been misinformed about other available options and the risks of refusing blood. The facts revealed that when Miss T expressed her refusal to blood transfusion and enquired about other alternatives, she was advised that the alternatives were less effective than blood, but

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[9] *Re T* [1992] EWCA Civ 18 at [45].

reassured that “transfusions were not often necessary after a caesarean section”.[10] The court found that there was no evidence to suggest that she had refused transfusion at all cost. SDM could remedy the situation at the time she expressed her refusal and when she enquired about other alternatives to blood products. She could be informed about the real possibility of being transfused with blood products if the alternatives did not work to save her life. Other relevant information includes the risks of not receiving blood products at all; that she might be risking her life if she refused at all. With this information, she may be able to arrive at an understanding of the nature and consequences of her refusal.

5.2.3 T-Type ADs: Some Applications of SDM Approach

T-type ADs involve ADs made by patients whose mental capacities are at issue, such as Miss E (anorexic) and Ms T (bloodletting patient). ADs under this category were open to doubt at the time of application. SDM may help to a certain extent because the patients were already incompetent by the time their ADs were sought to be implemented. It brings forth the question of the approach to be taken in the light of conflicting evidence between family members and the hospital, and conflict of evidence among family members.

5.2.3.1 Miss E: Patient Suffering from Multiple Disorders

Miss E in *A Local Authority v E* suffered from anorexia, alcohol abuse and personality disorder. She had made ADs refusing food, but the court found that she was mentally incompetent when she made the ADs. SDM offers the potential to help her get around the issue of capacity when she made the ADs. In making her ADs, apart from having her parents with her, and the mental health support worker, a doctor’s presence and assessment for the purpose of making ADs might be able to determine whether E possessed the mental capacity at the material time. The purpose of conducting the capacity assessment at that time was to show that any doubts about her capacity then could be ascertained. There is however one difficulty with such assessments. She might not be able to comprehend what the AD means, or the window of opportunity to determine her mental capacity is so slim to the extent that she would be generally categorised as not having mental capacity. E’s case demonstrated a complex situation due to her suffering a long standing illness, that SDM may not be able to play a meaningful role for her in a contemporaneous refusal, and less likely to be so in an AD. This is compounded by the approach of the court in presuming her to be incompetent at the time she made the AD by virtue of her current incapacity.

So what can happen is that SDM can have a limited role in terms of offering her support to help her build her capacity to achieve the stage where she can be determined

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[10] *Re T* [1992] EWCA Civ 18 at [15].

to be competent to make the AD. The support necessary will be commensurate with her mental capacity to a point where she can understand the nature and consequences of the refusal. While it was difficult to know with certainty that E had mental capacity at any given time, there were moments when she knew what was happening to her, where she fully appreciated her situation arising from her experiences as a person who suffered from mental disorder and anorexia. Thus, when E was in a lucid period then the doctors, counsellors or her care team could proceed with helping her make the AD, which would have been more possibly valid. Involving a doctor enables the doctor to understand the decision making context and clarify any misunderstandings. Arguably, such situations are still likely to be at least somewhat difficult, especially where E has battled her complex disorder for such a long time. It is quite likely therefore that Miss E would be found to be mentally incompetent and her AD invalid.

5.2.3.2 NHS Trust v T: Patient with Mental Disorder

Miss T was a patient who bled herself habitually to the point of requiring a blood transfusion, but she had made several ADs refusing transfusion because she perceived her blood as evil. The court found that she was mentally incompetent when she made the AD because her refusal had manifested from her mental disorder. The facts revealed that she had on several occasions attempted to make her AD and visited a doctor and a solicitor with a view to formalising her AD. SDM could have assisted Miss T in two ways: firstly, she could have been mentally assessed at the time when she went to the doctor's and to make clear her intention that she wanted to refuse blood transfusion in the future. There might be the opportunity to find a brief period of time when she could be mentally competent and to take that chance to explain to her about what would happen with her refusal. However, given that her views were a manifestation of a mental disorder, a doctor's assessment might not be given substantial weight compared to a psychiatrist. A psychologist or psychiatrist would be the more appropriate person to conduct capacity assessment on a patient like Miss T.

Secondly, even if the time is unsuitable to assess her capacity, there is the opportunity to build her capacity so that she can be mentally competent again. Whether her refusal manifested from her mental disorder can be elucidated once she had been properly assessed by specialists. As proposed in Miss E's case above, SDM could help build Miss T's capacity, although it may be difficult if not impossible, given the long-standing mental disorder that she suffered from. This could precede the support given when her capacity was being assessed. Miss T's case illustrated that while SDM might have helped towards building her capacity, it would be less likely to help establish that she had the capacity to refuse in this case. In terms of building her capacity, it might be helpful to have a record evidencing her mental capacity reflecting either her improved state of capacity or otherwise. This record of evidence would be valuable should the need arises for them to plan the next steps in their treatment plans.

5.3 Conclusion

The SDM approach has given rise to some questions about its actual impact in helping the intellectually disabled exercise their preferences, particularly, whether it would result in a more empowered person under a guardianship order.[11] Despite this, the critics acknowledged that SDM, to a certain extent, may potentially assist the intellectually disabled with managing their affairs, most significantly in creating an opportunity for existing support arrangements to be formalised or integrated into current framework[12] and on a personal, psychological level, promoting an "internal sense of control" in the process of being empowered, for example, through ADs and various other similar forward planning instruments.[13] Particularly, Kohn, Blumenthal and Campbell's research highlighted helpful concerns for the operation of SDM in reality. This aspect is of particular relevance to ADs in the sense of investigating the extent to which SDM would work in clinical practice, such as in an AD consultation and the subsequent creation of an AD.

A preliminary but important observation concerning the utility of SDM in the context of ADs can be made. People with intellectual and cognitive disabilities face additional challenges in reaching satisfying decisions compared to people who do not face such profound challenges. As such, the limitations highlighted by Kohn, Blumenthal and Campbell would more likely emerge in the context of people with disability in contrast to SDM in competent people seeking to be better informed in making decisions regarding future treatments.

It is recognised that support is as common as it is an essential element in our daily life. The range of support would differ, depending on the circumstances and the people who require such support. SDM removes some of the obstacles in an invalid AD and provides a higher degree of assurance to the binding status of ADs. People thinking of making future plans for medical treatment, such as Benjamin or people suffering from progressive illness such as AK would find that SDM makes a positive contribution to their expression of preferences, resulting in such wishes being more likely to be implemented. The T-type cases, on the contrary, presents a more complicated picture, involving a more intricate decision-making process with particular challenges regarding the amount of support necessary to exercise genuine preferences. However, this does not automatically render SDM futile. Regardless of the type of autonomy assumed in these special cases, support needs to be provided, which undoubtedly include the need for capacity building.[14] SDM is thus extended to

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[11] Nina Kohn, Jeremy Blumenthal and Amy Campbell "Supported Decision-Making: A Viable Alternative to Guardianship?" (2013) 117 Penn State Law Review 1111–1114, 1128; Nina Kohn and Jeremy Blumenthal "A critical assessment of supported decision-making for persons aging with intellectual disabilities" (2014) 7 Disability and Health Journal S40–S43; Terry Carney "Clarifying, Operationalising, and Evaluating Supported Decision Making Models" (2014) 1 Research and Practice in Intellectual and Developmental Disabilities 46.

[12] Ibid, at 1154.

[13] Ibid, at 1137, 1139, 1145.

[14] Mary Donnelly, 'Best Interests In The Mental Capacity Act: Time To Say Goodbye? 2016 24(3) Medical Law Review 318–332.

supporting them to express their preferences according to the continuity of their life story and what makes the decision meaningful in their own account. It is however, recognised that in reality, the support offered may, sometimes vary, depending upon the availability of the healthcare resources, physical infrastructure and healthcare staffing, particularly, the constraints of time. Additionally, SDM is envisioned to be occurring over a period of time, as reflected by the cases above, which is an important factor involving patients with multifaceted disorders. Therefore, broader institutional and systemic changes to the provision of mental health support to patients such as Miss E or Miss T is necessary to empower them to express their wishes.

Chapter 6
Regulating Advance Directives

6.1 Introduction

Regulating ADs requires balancing between competing interests of the state in protecting life and respecting the individual's right to make anticipatory treatment preferences. The more common regulatory approach among the jurisdictions discussed is the introduction of formal requirements as part of the condition for an AD to be valid and applicable. Some of the cases discussed have shown that compliance with formal requirements was essential in order for an AD to be upheld. I examine these formalities below, their advantages and drawbacks, alternative options and consider whether such formalities should be implemented.

6.1.1 Formalities and ADs

6.1.1.1 Writing

Being in writing is one of the formal requirements in jurisdictions with statutory regimes for ADs. An AD can be made either orally or in writing under the common law. Compared to a written AD, an oral AD suffers from a weakness in terms of ascertaining the existence of a prior expressed wish. Thus, the purpose of writing is to provide evidence of the existence of a prior expressed refusal and its terms, as well as proving the gravity with which the view was expressed. However, this does not mean that the AD will be accepted at face value. Under the MCA, an AD refusing life sustaining treatment has to be written, with a statement to the effect that the person making the AD has verified that the AD will apply even if life is at risk. The explicit reference to writing not only provides evidence as to the existence of the AD, but also that the person has intended it to apply at the specified circumstances.

H. Y. Chan, *Advance Directives: Rethinking Regulation, Autonomy & Healthcare Decision-Making*, International Library of Ethics, Law, and the New Medicine 76,
https://doi.org/10.1007/978-3-030-00976-2_6

While a written AD may be the most direct method of establishing its existence, another method that can provide evidence of a prior expressed wish is statements by people who know about the existence of such ADs or who are aware of the prior preferred wishes through their knowledge of, or conversations with the person. However, their evidence is not always accepted, due to a conflict of interest or where there is conflicting evidence among the people about whether an AD truly exists or otherwise. The cases showed that, while the courts do not expressly refer to the necessity of writing, a written AD helped by setting out the contents of the refusal, especially where the person had already become incompetent by the time of the hearing. Thus the written AD can 'speak' to the court about the prior expressed wish, before proceeding further to consider its validity and applicability. A written AD is thus preferable to an oral AD. A usual scenario involving a written AD is one where the person contemplating setting out his wishes would write down the wishes himself. This may unnecessarily constrain the meaning of writing and the intention of the person. As such, writing for the purpose of AD can include electronic mails and an oral AD which has been reduced to a written format by someone else, or that appears in an audio or video format.

6.1.1.2 Signature

Some statutory regimes also require an AD to be signed by the person who made it. The person's signature proves that the person had intended the AD to be effective or to show that the person has committed a conscious act. A signature need not necessarily be made by the person himself, especially where the person is unable to do so, due to physical impairments. It can be signed by another person at the direction of the person who made the AD. The absence of a signature should not be fatal to an AD, because while it represents that the person has confirmed that the AD is made by him, it does not necessarily confirm the content of the AD and what the terms are. With technological advancement, it may even be possible that ADs can be uploaded onto a database or registry where the personal signature can be dispensed with (or if not feasible, and can be replaced with an electronic signature). The practice of actual physical signatures is increasingly being replaced by other means of confirmation in the commerce and banking industries, and this could apply to ADs.

6.1.1.3 Witnessing

A witness to the AD can serve the purpose of proving that the signature is valid, or that the content has been confirmed by the person who makes the AD. A witness can also serve the purpose of providing evidence that the person who made the AD was mentally competent, such as the case under the Singapore AMDA. Having the witnessing requirement may have these benefits, but the cases did not suggest that this was an essential requirement. If the purpose is to prove that the signature is valid, then this may not be necessary. A person who suffers from physical disabilities or people with estranged family members or where relatives are unknown may find it difficult to satisfy this requirement, if it was made mandatory. On the other hand, if the purpose of witnessing is to ensure that the person is mentally competent, or is acting voluntarily and with full understanding of the nature and consequences of the refusal, then making this witnessing aspect mandatory may have its merits. This will then require a consideration of the appropriate qualifications of the witness, such as possessing the requisite expertise in a particular field. Where a healthcare professional becomes a witness to a patient's AD, there may be an assumption that the healthcare professional has verified the patient's mental capacity.[1] On this issue, the British Medical Association encouraged doctors to record notes regarding the patients' mental capacity, including where there is no reason to doubt their capacity.[2] A witness who can testify to the court later concerning the person's capacity, voluntariness and understanding can assist the court in determining the validity of the AD, although this role is by no means determinative. Nonetheless, a witness in this capacity may affect the outcome of the contested AD.

6.1.1.4 Prescribed Form

There are numerous forms available from hospitals, hospices and residential care homes for setting out wishes and treatment preferences. The AD laws in Canada and Singapore provide specific forms for ADs. If a person does not use the prescribed AD form, as in the case of Singapore, then the AD will be invalidated. The requirement of prescribed form is additional to the common law position. While forms may be helpful as a guide and for consistency purposes, they may not necessarily reflect the autonomous expressions of wishes. For example, a standard refusal form where a patient ticks the boxes or crosses out any statements does not reveal whether the patient truly understands what the person is refusing or otherwise. It only shows that a refusal exists; a refusal which may be in form rather than in reality.

6.1.2 Non-compliance with Formal Requirements

The *Re D* decision highlighted the consequences of not complying with the formalities of an AD refusing life sustaining treatment under the MCA.[3] In that case, Mr D's AD refusing life sustaining treatment failed to comply with the requirements of ss 25(5) and 25(6) of the MCA 2005 because it had not been witnessed and did not include a formal verification to the effect that he would want the AD to apply to the treatment even when his life was at risk. The need to verify explicitly that the

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[1] British Medical Association "Advance Decisions and Proxy Decision-making" in *Medical Treatment and Research: Guidance from the BMA's Medical Ethics Department* (BMA, 2007) at 6.

[2] Ibid.

[3] *Re D* [2012] EWHC 885 (COP).

AD applies notwithstanding life is at risk reflects the approach of the legislature, which errs on the side of preserving life in case of doubt about the validity of the AD. Invalidating an otherwise valid AD on the ground of non-adherence with the statutory form is a technical impediment that defeats an otherwise valid AD. Of more importance is ensuring that the decision-making process contributes to arriving at a genuine, authentic expression of autonomy. The cases show that the person's mental capacity and the circumstances at the time of making the AD are more important than whether the specified form has been used. The courts would like to know what happened at the material time, just like in a contemporaneous refusal. This can be illustrated with Mr. AK's decision, where the meticulous process by which his wishes were recorded, explained and reconfirmed was sufficient to assure the people who sought to implement the AD of the authenticity of the refusal. The Canadian approach is the preferred approach where forms are available but their use is not mandatory; as such, failure to use the prescribed form does not have the effect of invalidating an otherwise valid AD.

The issue of non compliance with formalities raises the question of educating the doctors about the importance of complying with formal requirements. A doctor's involvement cannot be discounted in AD disputes as exhibited by the cases, mostly in determining a patient's mental capacity. On the other hand it must be acknowledged that not everyone has access to these legal forms. Some would not know where to start or find them or be aware of the need for a prescribed form. Requiring technical compliance when the substance has been clearly conveyed the person's wishes give rise to inappropriate obsession with forms, thereby prioritising form over content. Those who do not use the form should not be 'punished'. This will be considered more fully below.

6.1.2.1 Liability of Doctors Who Rely Upon or Refuse to Comply with ADs

The question about the liability of doctors who refuse compliance with an otherwise valid AD is more complex. Doctors are generally protected from liability when they act in accordance with ADs that do not raise any doubts about validity. A doctor can refuse to comply with an AD on the ground of conscientious objection, but this only permits the doctor to transfer the care of the patient to another doctor.[4] Some laws have

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[4] See NZMA Position Statement on Advance Directives at [11]; General Medical Council (2018) "Personal beliefs and medical practice". https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/personal-beliefs-and-medical-practice/personal-beliefs-and-medical-practice#paragraph-24; British Medical Association "Advance Decisions and Proxy Decision-making" in *Medical Treatment and Research: Guidance from the BMA's Medical Ethics Department* (BMA, 2007); Compassion in Dying "Making and Implementing Advance Decisions: A Toolkit For Healthcare Professionals" (September 2015 London). https://compassionindying.org.uk/wp/wp-content/uploads/2015/09/CiD_HeathcareProfessionalsToolkit_A4_WEB.pdf. Accessed 2 July 2018; Jere Odell, Rahul Abhyankar, Amber Malcolm and Avril Rua "End-of-life care. Conscientious objection in the healing professions: a readers' guide to the ethical and social issues" (May 31, 2014).

permitted doctors to refuse compliance with ADs on the ground that compliance will be contrary to good medical practice or inconsistent with the relevant professional standards.[5] The good medical practice and professional standards grounds are more likely to attract debate, because this will implicate the application of an otherwise valid AD. If a doctor is permitted to refuse compliance on this ground, the person's autonomy to refuse treatment in advance is undermined.

6.2 Should the SDM Approach Be Formalised?

Bearing in mind the various advantages and drawbacks of instituting formalities, it is thus important to consider whether formalities should stay. Before considering whether SDM should be formalised in the context of ADs, I consider some of the SDM models generally, which appear within the framework of guardianship and substitute decision-making laws. For example, Ireland's Assisted Decision-Making (Capacity) Act 2015 introduced SDM for people who are anticipating incapacity at a future time to arrange for decision-making assistance agreements or co-decision-making agreements.[6] The decision-making assistance agreement relates to specific decisions while the co-decision-making agreement requires a higher level of support in the form of information provision and explanation, alerting the person to alternative options, establishing the person's preferences, assisting with communicating such preferences, as well as ensuring the implementation of the decision to the fullest extent possible.[7] Even though the co-decision-maker makes the decision together with the person requiring support, the latter is the ultimate decision-maker.

A formalised approach to SDM means that the agreements and the parties involved have legal status in the eyes of law. Mary Donnelly, in commenting on the law, observed that while the mechanism has the potential to improve decision-making, the possibility of undue influence cannot be discounted.[8] Other models of SDM include informal arrangements, agreed between the parties, or the 'non-statutory model' in South Australia with the addition of independent persons to scrutinise the arrangement between the support person and the supported person.[9] Generally, where SDM is recognised in the law, they are either recognised in general without necessitating legal status, or granted legal standing where the SDM arrangement entails powers and consequences among the parties to the arrangements.[10]

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[5] See for example, in some Australian AD laws: Advance Care Directives Act 2013 (SA), s 36(3), Powers of Attorney Act 1998 (Qld), s 103(2).

[6] Mary Donnelly, 'Legislative Comment: The Assisted Decision-Making (Capacity) Act 2015: implications for healthcare decision-making.' 2016 22(2) MLJI 65.

[7] Ibid.

[8] Ibid.

[9] Terry Carney & Fleur Beaupert, 'Public and Private Bricolage—Challenges Balancing Law, Services & Civil Society in Advancing CRPD Supported Decision Making' 2013 36(1) UNSW Law Journal 175–201.

[10] Ibid., referring to the examples of Canada and Australia.

In the context of ADs, there are two options in implementing SDM. One option is to make SDM compulsory. This option would require people wishing to make ADs binding on the healthcare professionals to follow the SDM procedures, which include undertaking mental capacity assessment by the relevant specialists for the purpose of making ADs, recording all decisions in written form, revalidation and ensuring that a proper trail of record be taken. The main requirement under the compulsory SDM regime would involve working with a healthcare professional in preparing the AD. This may allow a capacity assessment and the opportunity to ensure that the person knows what he or she is refusing. Following this approach would ensure that the AD is at least minimally informed and not based on any assumptions or mistaken beliefs about prognoses or treatment options. The compulsory feature results in "trading-off" the person's autonomy, because the person now can no longer make an AD as he wished, unlike the common law position. Under this system, it means trading off the autonomy to make a binding AD without utilising the SDM process for a more important use of autonomy, which is making a clear, accurate and informed AD. This option thus imposes a responsibility on the person to adhere to the SDM process, failing which the AD is invalid.

On the other hand, this option can be viewed as a legitimate interference on the person's autonomy because people who follow this option would be better off generally in the sense that there is a higher likelihood that their ADs will be upheld. This stricter regime may be paternalistic, but the end result would be for the person's own good. A danger with this option is that ADs that do not go through this rigorous SDM process may be excluded, or where one or more requirements fail to be met will be, unfortunately invalidated. This would result in an unsatisfactory situation for AD and suffer the same fate as the *Re D* case.[11] This option does not seem to be viable for ADs and risks creating a stringent process that defeats the purpose of ADs. Statutes may inadvertently restrict an otherwise valid but improperly executed AD in compliance with the formalities of the statute.[12]

The second option is the preferred approach, which is to establish a special regime for ADs incorporating the SDM approach, but which is not mandatory. The purpose of this option is to maximise the probability of people's ADs being binding. Pursuant to this option, the appropriate health authority can create a nationally approved document for ADs. This document can be streamlined across the hospitals, and organ-

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[11] Other examples include the Advance Care Directives Act 2013 (SA), s 11(2) where the failure to complete a mandatory section in the AD will invalidate the AD; in New Zealand in the area of relationship property, the failure to comply with the formalities of contracting out of the equal sharing regime between spouses and partners render the agreement between the parties void: Property (Relationships) Act 1976, s 21F.

[12] Lesley Castillo and his colleagues found that execution requirements such as the requirement for written and signed ADs in statutes impeded the effectiveness of ADs in a survey of AD statutes across the states in the US.: Lesley S Castillo and others "Lost in Translation: The Unintended Consequences of Advance Directive Law on Clinical Care" (2011) 154 Ann Intern Med 121 at 123. Likewise, Lindy Willmott has pointed out that the law governing ADs in Queensland restricted the operation and binding effect of ADs: see Lindy Willmott "Advance Directives to Withhold Life-Sustaining Medical Treatment: Eroding Autonomy through Statutory Reform" (2007) 10 Flinders Journal of Law Reform 287 at 289.

isations such as care or nursing homes, resulting in a consistent approach throughout the country. This document, in a written format is created together with a doctor or a qualified nurse with expertise in ADs. The doctor would have the chance to observe the person and make a finding in respect of the person's mental capacity, while verifying the person's understanding of the nature and consequences of making particular treatment decisions. This process would also allow the doctor to refer the person to a third party or independent specialists for further consultations where the need arises.

Following the discussions between the doctor and the person in making ADs, the notes and statements would be recorded and reviewed regularly as agreed by the person and the doctor. During the review process, there will be the opportunity for updates to be included, and revalidating any preferences and discussions made. Such records of discussions which are appropriately maintained and updated are valuable sources of evidence that can shed light on questions about the circumstances surrounding the making of the ADs. It would assist in answering queries regarding the existence or currency of the ADs, providing insights into the event at that particular time. This becomes increasingly important in more complex cases. The cases have shown that the courts view a doctor's involvement favourably and almost mandatory in most cases, usually seeking positive proof of mental capacity through the doctor's evidence. The courts too wanted to know that the person had understood the nature and consequences of the refusal.

A presumption of validity of ADs overcomes the problem of second-guessing people who have ADs. In order to introduce the presumption of continued validity of AD into the regime, the SDM process could incorporate several measures. For example, in the case of Benjamin, a doctor could emphasise the importance of updating his AD as often as necessary, or when he changes his mind. The doctor could stress the difficulties that could arise should he change his mind about his refusal to accept blood transfusion without amending his AD. Benjamin would then be aware of the possibility that the doctor would comply with his wishes when he had changed his mind. It would give him the opportunity to reflect on what he would do to accommodate the possibility. Another measure related to updating an AD is introducing a system of regular confirmation of the AD, such as an annual confirmation of the previous AD. This would entail reminders or notifications being sent to the person by a family doctor, or solicitor as the circumstances require. It would be similar to, for example, a reminder for vaccination. This reminder may come with an alert that regardless of whether any changes have occurred, the person will need to review the AD and re-sign it. Such an action indicates that the AD is presumed to still reflect the person's wishes. These measures minimise the likelihood of changes occurring, although they could not possibly eliminate all changes that might occur.

A person who uses the SDM process will have an AD that will be presumed to be binding. This is similar to the presumption of effectiveness of an AD utilised in the Canadian statutory framework. Such ADs would give rise to the opposite presumption from that used in *AE*. In *AE*, Munby J proposed that the burden of proving the continued validity and applicability of an AD was on the person asserting its continued validity. Where an AD has been prepared using the SDM process, the presumption should be that the AD remains binding until the contrary is proven. As such, the burden of proof on a balance of probability will be on the person seeking to challenge the AD on the grounds that subsequent changes had occurred, or that the person was incapacitated at the time it was written, or had not acted voluntarily, or had failed to understand the nature and consequences of the refusal. Although it is possible that capacity assessment will not necessarily result in a unanimous or consistent finding among the specialists, engaging in such assessments will make the AD less likely to be doubted on the ground of incapacity. Engaging in the SDM process orientates the person's mind and thinking into reflecting seriously about his or her wishes and intentions for treatment refusal. ADs that were made without engaging in the SDM process will not automatically become invalid, but such ADs run the risk of not being presumed as binding, and the burden of proof may not necessarily be on the person challenging it. Additionally, the presumption that the AD is binding precludes the application of an approach that readily errs on the side of saving life in the event of conflicting evidence from family or friends about the validity of the AD.

This option could also integrate existing advance care planning activities within its regime. Recent developments revealed a lack of engagement in future planning from the underserved population, comprising of indigenous people and an increasingly culturally diverse society, mostly due to a reluctance to engage in end-of-life discussions.[13] Discussions about end-of-life care within advance care planning, culminating in ADs would enable the indigenous communities to express their wishes to be close to their families as they approach the end-of-life, rather than dying in unfamiliar places, such as the hospital.[14] This would entail an ongoing process, supported by educational measures in promoting the use of ADs among the intended population. For example, the Australian Healthcare and Hospitals Association in its position statement in December 2016 outlined its support for ADs and advance care planning within the end-of-life care framework. According to them, measures to provide a better end-of-life care framework incorporating advance care planning should include improved integration between ADs records and various units in healthcare services, such as the hospitals, geriatrics or primary care. A coordinated approach will translate into better care outcomes to the people, where care is provided according to expressed wishes. One way is by creating a specialised team of trained clinicians whose expertise are in advising patients about ADs. Doctors in primary care or other health services who received requests for information or discussion about ADs can refer them to the specialised trained clinicians for further action. This line of approach would on one hand alleviate the problem of time constraints faced by doctors in primary care settings and on the other hand, ensure that the patients receive guidance and support in the process of expressing their treatment preferences, wishes and

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[13] E Waran, S Wallace and J Dodson-Jauncey, 'Failing to plan is planning to fail: advance care directives and the Aboriginal people of the Top End' 2017 206 (9) MJA 377–378 https://doi.org/10.5694/mja16.00843.

[14] Ibid.

needs according to their values and beliefs. Resources needed to build specialised teams of ADs clinicians can then be pooled to these people, with joint collaborations from relevant health units, such as geriatrics or palliative care.

6.3 Golden Rules for Making Advance Directives

6.3.1 A-Type ADs

6.3.1.1 Validity

As these types of ADs are made when the person is already unwell, a person must go through a capacity assessment as proof that the person is mentally competent at the time of making the AD. As demonstrated by AK, the treating doctors and independent specialists have confirmed that AK possessed the capacity to refuse ventilation. They were able to confirm that he had understood the nature and consequences of the refusal. Such confirmation and any information provided during the course of consultation relating to the illness, prognoses, treatment options and the person's preferences would be well advised to be recorded. The same applies to recording statements or observations about a person's voluntariness.

6.3.1.2 Application

The main issue for A-type ADs was whether the patient had changed his mind since the AD was made. Such patient would be well advised to review and revalidate the AD periodically to demonstrate that despite the changes the preferences remained fixed, or that the changes had affected the person that the AD no longer represented the person's wishes.

6.3.2 B-Type ADs

6.3.2.1 Validity

B-type ADs raised questions about the validity at the time the ADs were made, because the person was not unwell at the time and had no reason to consult a doctor, thus, precluding the opportunity to consult. A person such as Benjamin, who wished to make a binding AD, may be well advised to have his mental capacity assessed for the purpose of making an AD pursuant to the SDM process. This is especially crucial where it involves a healthy person who refuses standard life saving treatment; in such a case their capacity is bound to be questioned.[15] Engaging in the SDM process is strongly recommended for B-type ADs. In terms of understanding the nature and consequences of the refusal, depending on the type of treatment the person has chosen to refuse, it is important that the person understands what he is refusing and appreciate the nature and consequences of refusing treatment. There will be the opportunity to clarify any misconceptions about particular treatment. Although a person need not explain the reason for refusing treatment, given the nature of the refusal (for example if it involves a standard life saving procedure) and the person who is relatively healthy and competent, it is advisable to record the reasons for the refusal.

For Jehovah's Witnesses, the question of their faith and whether they are acting voluntarily or otherwise are not always easily separable. Care should then be taken to ensure that they understand what they are refusing and the consequences of such refusal. In terms of provision of information, SDM potentially helps with refining information on treatment options and the consequences of refusing into easily understandable and manageable portions for the individual to understand. Then again it will be dependent on the capacity to comprehend such information in order to arrive at a decision.

6.3.2.2 Application

The SDM process here include alerting the person to the fact that he had intended the AD to apply in the specified circumstances, or under what circumstances it can still be applied. A person such as Benjamin would then be aware that the range of foreseeable possibilities may not be exhaustive within his contemplation and then he would consider the scope in his AD. For Jehovah's Witnesses, they should also be advised under the SDM process whether their refusal is intended to apply at all circumstances or otherwise. The advice should emphasise the importance of amending or revoking the AD if they change their minds.

Unlike A-type ADs where the room for changes to occur was slim as the medical prognosis and treatment options were clear and known, B-type ADs were open to the possibility of changes arising from change of mind, change of personal circumstances and change in treatment options, which could exist together or separately. Therefore it is imperative that patients under this category are advised about the likelihood of these changes occurring and what they should anticipate if such changes were to materialise. While it is impossible to nail down every possible change for a distant future, emphasising the real possibility of these changes occurring can bring to their attention the importance of accommodating such changes. Revalidating the AD as often as the person wishes is recommended as it may remove a challenge under this

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[15] An example drawn from the area of wills and trust is the "golden rule" of testamentary capacity where a prudent practice is to have the testator's mental capacity (especially an older testator) assessed by a doctor despite the absence of mental incapacity. See Charles Holbech "Has the golden rule lost its lustre?" (2012) Trusts and Estates Law & Tax Journal 10–13.

heading but it does not eliminate the doubt entirely if the person eventually changes his mind but had already become unable to communicate. As such, revalidating the ADs helps minimise the doubts that may potentially arise after the making of the ADs.

6.3.3 T-Type ADs

6.3.3.1 Validity

A capacity assessment for individuals under T-type category will be much more complicated than A-type and B-type cases. These individuals suffered from mental disorders with various levels of severity. A capacity assessment may be helpful to determine the level of support needed to build their capacity to make decisions, although such assessment may not always be possible. It may be difficult to ascertain whether at any point of time the individual possesses the capacity to refuse treatment. Similarly, it may be possible that there would not be unanimous judgment of capacity. The cases have shown that capacity assessment is a complex area. Patients who suffer from different types of mental disorder may require more careful and specialised capacity assessments, different from a standard capacity assessment for the purpose of making ADs. It becomes necessary then for T-type ADs to involve the relevant specialists, although involving them in the process may not determine that the patient will have capacity.

6.3.3.2 Application

SDM can help individuals under this category when they are making their ADs in putting together a clear and precise AD. They should also be advised whether their refusal is intended to apply at all circumstances or otherwise and to recognise the significance of amending or revoking the AD if they change their minds or where they anticipate changes in their personal circumstances. As mentioned above, for T-type ADs, even if the AD has been established as valid, it may be open to a challenge on the basis of subsequent changes, if there was evidence to suggest that the AD had not survived such changes. It is essential that individuals under this category are advised about the possibility of subsequent changes occurring, so that they may well anticipate what should be done in the event of such changes happening. The person may be well advised to reconfirm the terms of the AD as necessary to minimise the likelihood of a dispute under this heading. Where the AD is made under the special regime with SDM, it will be presumed as valid and binding, until proven otherwise. The burden of proving that the subsequent changes had invalidated the AD will be on the person seeking to revoke it. The use of family, close friends and support persons at the time of making the AD may help them in terms of identifying suitable or trusted persons that the doctors can refer to when a conflict occurs.

Recognising the significance of the involvements of doctors and healthcare professionals, while acknowledging the time constraints they may have, it may be possible to have trained facilitators with experience making ADs to speak to the patients as a preliminary step. This step occurs prior to a consultation with the doctor who will then advise the person about treatment options, capacity assessment and provision of information. The person's wishes are then recorded in writing, with the contents communicated to and confirmed by the person as representing the true wishes. This, however, does not preclude them from making an oral AD but usually where a consultation occurs, there is bound to have a trail of record about such discussions taking place. The doctor then will highlight the importance of reviewing the AD, depending on the circumstances of the person, such as different types of ADs made at different stages of life. The circle of support would be wide enough to include family, close friends, social support workers or anyone that the person chooses. Their involvement and the possible measure to address conflict of evidence have been discussed above.

6.3.4 Application of SDM in Jurisdictions with Statutory Regime

SDM can apply in jurisdictions where AD statutes are applicable. The formal requirements in the statutes provide some guidance in respect of what to expect of a valid and consequently binding AD. For example, in order to make a valid AD refusing life sustaining treatment in England, SDM can help the person fulfil the requirements of the law, especially under sections 25(5) and 25(6) of the MCA 2005. The person can be assisted with producing a statement that shows that he or she has verified the wishes to apply even if life is at risk. Such a statement would be reduced into writing, signed and witnessed. If the person is physically disabled (such as AK or XB), then the doctor or care team can assist him in reducing the wishes into writing, which can be carried out in his presence and after that signed under his direction. Producing a statement like this will include assessments of mental capacity, having the doctor explain the consequences of refusing treatment and the effect of the AD on the person's life.

Additionally, in the MCA, there is some recognition of SDM in respect of determining a person's best interest, where the person is supported in playing a role in the decision-making process affecting the person's care, and where necessary, including assisting with improving the person's capacity. SDM can likewise apply in the Canadian jurisdictions. As such, integrating the SDM approach as appropriate into current regulatory structure obviates the need to enact a separate, new framework to replace the existing statutory framework.

6.4 Conclusion

This book has provided an additional alternative to some of the pressing and practical problems with making ADs, with reference to the legal approaches and the AD debates. The courts' approach towards ADs suggested that they readily erred towards the presumption of saving life when doubts arose about the validity of the AD. Some jurisdictions have attempted to clarify the status of ADs by establishing formal requirements to make valid ADs, such as writing, signing, dating and witnessing an AD. There are parallels between how each jurisdiction strives to remedy the situation. Most jurisdictions specify the use of ADs by defining under what circumstances ADs are valid or binding. The statutory provisions clarified the common law rules about the use of ADs and the position of healthcare providers, as well as instituting additional requirements to making ADs. However, introducing formal requirements has the potential to invalidate an otherwise valid AD, as some research and cases have shown. Such formalities have unfortunately defeated the purpose of ADs.

The common interpretation of autonomy is, generally speaking, one of non-interference; competent patients are permitted to make their own decisions about healthcare treatment, free from medical coercion or undue external influence. This conception of autonomy is inadequate for ADs. Rather, autonomy for the purpose of ADs needs to be reconceived to include an element of "empowerment". In this sense, empowerment has the dual effect of empowering the individual and enhancing the reliability of the AD. This supportive approach to an individual's decision-making is particularly appropriate to ADs. It ensures the initial validity of the AD and allows for subsequent changes to be accommodated. Empowerment is realised through the SDM process. While SDM was originally used for physically and mentally impaired people in making decisions, its application to ADs is appropriate because of the distinctive characteristics of ADs. SDM removes some of the difficulties that are present in an AD, as evident from a spectrum of decision-making between a contemporaneous refusal and an AD where changes are liable to occur. SDM thus attempts to anticipate these difficulties and installs solutions while the person is still able to participate in the process. As a result, SDM helps ADs achieve a higher likelihood of becoming binding compared to ADs made without the SDM process, by embodying ADs with many of the qualities of a binding contemporaneous refusal.

An AD within a system that incorporates the SDM process provides an option for people wishing to increase the likelihood that their AD will be regarded as binding. The SDM option retains the flexibility of making common law ADs, but the caveat is that such common law ADs assumes the risks of being not binding. SDM would be most effective at the time the AD is created. It lends more reliability to the decision-making process and stronger assurance to the implementing parties by showing that the person was mentally competent, making a voluntary decision, and had understood the nature and consequences of the refusal. The SDM process invites the participation of support persons, family members or close friends when the person makes the AD, which would be helpful when the AD is implemented. It provides an opportunity for trusted people to be nominated as substitute decision-makers or to act as the main reference point in the event conflict arises. Questions about change of mind and whether the decision still represents the person’s wishes invariably remain. Incorporating and implementing SDM into clinical practice require further practical consideration, such as the available resources within the healthcare system in offering these services and questions regarding its sustainability, as well as time constraints faced by doctors in carrying out AD consultations. While it has its limitations, the proposal incorporating the SDM approach to ADs is a step towards addressing some of the main concerns in ADs disputes, by introducing a decision-making process that pre-empts questions about the ADs’ validity. The SDM approach points us in the right direction and gives us some insight into the problems that need to be resolved before ADs become widely accepted in the medical profession and in our legal system.

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