Advance Directives: Concerns regarding the expansion of Informed Consent and the need for Stricter Regulations.

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A dissertation submitted in partial fulfilment of the degree of Bachelor of Law (with Honours) at the University of Otago

October 2016

Acknowledgements:

I would like to thank my supervisor Jesse Wall for his constant support throughout this process. His guidance and insight was instrumental in producing this final product. Thank you not only for supervising this dissertation but also for inspiring my interest in medical law and specifically Advance Directives. Your extensive knowledge in this area, and your advice has been extremely valuable.

To my friends and flatmates, thank you for putting up with me during this process. Thank you for keeping grounded and getting me out of the library for some much needed breaks.

And finally to my family who made my time at Otago University not only possible but who supported me unconditionally throughout this process. Thank you for keeping me positive and putting things into perspective when it all seemed too much. A special thank you to my mother who suffered through numerous phone calls and various drafts. Thank you for your valuable feedback and endless encouragement.

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Introduction:

Modern medicine has seen advancement and innovation, however in some cases this has caused the undesirable prolonging of an individual's life.[1] Often this leads to periods where they lack the capacity to make treatment decisions and thus their individual autonomy (right to self-determination) is compromised. An Advance Directive (AD) attempts to resolve this problem by allowing for an individual with capacity to articulate their refusal of medical treatment in anticipation of a period where they will become incapacitated. This "advance" refusal persists only becoming enforceable when this "future period" of incapacity results. An AD therefore protects an individual's autonomy by preserving their wishes and later (when incapacity occurs) allowing these wishes to be assessed.[2]

The law ensures that where a patient with capacity has made a contemporaneous refusal (CR),[3] doctors cannot treat that person.[4] The intention of ADs was to expand this ability to refuse treatment, so that one's autonomy survives their loss of capacity. As even contemporaneous refusals are "at least minimally prospective"[5] expanding informed refusal was reasonable in an effort to better protect autonomy. Theoretically the only difference would be that the decision was more prospective.[6] However the increased lapse of time actually meant anticipatory refusals were radically different.[7] The increased delay (time lapse) between creation and implementation gave rise to novel problems distinct only to ADs.[8] As CRs are made in contemplation of a specific

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[1] Alasdair Maclean "Advance Directives and the Rocky Waters of Anticipatory Decision-Making" (2008) Medical Law Review 16 at 1; and Cordelia Thomas "Refusal of Medical Treatment by way of Advance Directives" (2001) New Zealand Family Law Journal 3 FLJ No 9 233 at 233.

[2] Ibid.

[3] A contemporaneous refusal is simply a refusal to consent to medical treatment in the immediate present. For example one is advised to have open-heart surgery, however after being fully informed of the procedure they refuse (for whatever reason) to consent to undergo the surgery.

[4] Health and Disability Commissioner (Code of Health and Disability Services Consumers Rights) Regulations 1996, Schedule 1, cl 2, Right 7(1) "Services may be provided to a consumer only if that consumer makes an informed choice an gives informed consent, except where any enactment, or the common law, or any other provision of this code provides otherwise"; and Health and Disability Act 1994, Section 20(1)(a) "the principle that, except where any enactment or any provision of the Code otherwise provides, no health care procedure shall be carried out without informed consent."

[5] Alasdair Maclean "Advance Directives, Future Selves and Decision Making" (2006) 14 Medical Law Review 291 at 291.

[6] Ibid, at 293.

[7] Maclean "Advance Directives and the Rocky Waters of Anticipatory Decision-Making", above n 1, at 1.

[8] Ibid, at 1-2.

treatment in specific circumstances, the refusal is informed[9] and subsequent changes in circumstances are unlikely. However with ADs the increased time lapse leads to increased difficulties in ascertaining whether the refusal was informed (prospective ignorance), and also whether subsequent changes invalidated prior instructions (radical change in circumstances). These two uncertainties challenge the underlying aim of ADs causing doubts as to whether individual autonomy is accurately represented.

This dissertation will firstly examine the current approach for ADs drawing comparisons with CRs. This includes an assessment on individual autonomy and whether this provides justification for a lower standard of "informed" refusal. Secondly this dissertation will address problems of uncertainty encountered with ADs and how these affect its validity. The focus will be on problems that directly result from this increased time lapse, with reference to specific examples. Finally, the dissertation will offer some recommendations reflecting on the shortcomings in the current legal approach and the problems identified. The benefit of such an undertaking is to ensure ADs are given appropriate legal recognition so they can adequately protect individual autonomy. This dissertation will not attempt to displace this paramount status of autonomy but rather revise the current legal approach so that ADs are better equipped to serve their purpose.

[9] Health and Disability Act, Section 20(1)(a).

Chapter I. Descriptors of the Law; Contemporaneous Refusal and Anticipatory refusal:

Advance Directives (ADs) attempt to expand the legal concept of informed consent in order to allow refusals to be made in anticipation of a future circumstance (prospectively). Such expansion allows individual autonomy to be preserved in situations where a patient temporally or permanently lacks capacity. An AD is essentially a representation and recognition of a legally competent patient's choice.[10] They are "a mechanism for individuals with capacity to say what they would like to happen in the future if their mental capacity becomes impaired."[11] The focus of this chapter is to establish the parameters of the law regarding ADs. Firstly it will outline the right of refusal and it's underlying rationale (individual autonomy.) Secondly the current legal approach for both CRs and ADs will be assessed. Finally a comparison of CRs and ADs will be undertaken, and the different requirements of informed refusal will be evaluated. In this comparison the notion of individual autonomy will be assessed as a possible justification for the lower legal standard applied to ADs.

A: Right of Refusal: Individual Autonomy and the need for Consent:

1. The principle of autonomy:

ADs are appealing due to their commitment to individual autonomy[12] namely their ability to give effect to people's treatment decisions.[13] Autonomy however is a rather elusive concept that is often "used in an exceedingly broad fashion."[14] Literally it means an individual's ability to "self –rule."[15] In the context of medical law it is largely described as the principle of self-determination; notably the legal right we

[10] New Zealand Medical Association "Member Advisor Service Information Sheet" (2015) NZMA <https://www.nzma.org.nz/__data/assets/pdf_file/0016/17008/AdvanceDirectives.pdf> at 1.
[11] Ibid.
[12] Alexander Capron "Advance Directives" in Helga Kuhse and Peter Singer *A Companion to Bioethics* (Blackwell Publishing, Massachusetts 1998) 261 at 261; Where he states Advance directives "embody the fields commitment to the principle of individual autonomy."
[13] Ibid.
[14] Gerald Dworkin *The Theory and Practice of Autonomy* (Cambridge University Press, Cambridge, 1998) at 10.
[15] Alasdair Maclean *Autonomy, Informed consent and Medical Law: A Relational Change* (Cambridge University Press, New York, 2009) at 10.

have to determine our own destiny.[16] It refers to our ability to choose our own course of action (what medical treatment we will subject to) in accordance with our life values and plans (critical interests).[17] In the context of medical law individual autonomy namely our ability to make "self-regarding decisions"[18] is of paramount importance. Ultimately individual autonomy is best described as the ability one has to "determine one's own beliefs, values, goals and wants, and to make choices regarding matters of practical import to one's life free from undue duress."[19]

Autonomy, particularly in the context of ADs has been the source of extensive debate. The disagreement revolves around the primacy autonomy gives to people's critical interests (long-term values such as career goals) at the cost of their experiential interests (current temporary interests such as happiness).[20] Dworkin's example of Margo (a dementia patient)[21] best describes this tension. In the case of Margo an AD protects her critical interests by upholding a refusal made prior to her loss of capacity, ignoring her current experiential interests; (her happy daily existence).[22] Writers such as Dresser argue the dominance of autonomy means critical interests are wrongly prioritised.[23] She argues one's prior critical interests have been surpassed by the experiential interests of this incapacitated patient; and her actual experiences of a

[16] Loane Skene *Law and Medical Practice: Rights, Duties, Claims and Defences* (2nd edition Lexis Nexis Butterworths, Australia , 2004) at 85; and *Airedale NHS Trust v Bland* [1993] AC 789 (HL) at 846; Per Lord Goff "if an adult patient of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interest to do so…. To this extent the principle of the sanctity of human life must yield to the principle of self-determination."

[17] Roger Dworkin "Medical Law and Ethics in the Post-Autonomy Age" (1992-1993) Indiana Law Journal 68 Ind. L.J. 272 at 272; and Dworkin *The Theory and Practice of Autonomy*, above n 14, at 14.

[18] Maclean "Advance Directives, Future Selves and Decision Making", above n 5, at 293; and J.K. Mason, C.T. Laurie M. Aziz *Mason and McCall Smith's Law and Medical Ethics* (8Th Edition Oxford University Press, Oxford 2011) at 65. There is a "strong moral conviction that everyone has the right of self-determination with regard to his body, the common law has long recognised the principle that every person has the right to have his bodily integrity protected against invasion by others."

[19] Catriona Mackenzie and Wendy Rogers "Autonomy, vulnerability and capacity: a philosophical appraisal of the Mental Capacity Act" (2013) 9 International Journal of Law in Context 37 at 42; and Jonathan Herring "Peter Skegg and the question No-one Ask: Why presume Capacity?" in Mark Henaghan and Jesse Wall (eds) *Law, Ethics and Medicine: Essays in Honour of Peter Skegg* (Thomson Reuters, New Zealand, 2016) at 41.

[20] David Shaw "A Direct Advance on Advance Directives" (2012) Bioethics Vol. 26 Issue 5 at 272-270.

[21] Maclean "Advance Directives, Future Selves and Decision Making", above n 5, at 295.

[22] Ibid.

[23] Rebecca Dresser "Life, Death and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law" Arizona Law Review 28.3 (1986) 373; at 373-405.

medical condition should be paramount.[24] Parfit further questions whether ADs even captures one's autonomy in the first place.[25] According to Parfit there is a lack of psychological connectedness between our previously competent self and this now incapacitated self.[26] As we develop we have this chain of successive selves, but this is broken when an individual can no longer recall their former self. [27] This is because the moral relationship between the two selves has lapsed.[28] Therefore the Margo prior to the progression of Dementia and the Margo now affected by dementia are two different people.[29] Consequentially upholding an AD is effectively prioritising the interest of earlier competent Margo, and ignoring the interest of the incapacitated Margo.[30]

This debate is important in understanding the background and underlying considerations of consent. However for the purpose of this dissertation the orthodox preference for Dworkin's approach favouring critical interests will be presumed to be the correct position. The presumption will be that autonomy is correctly focused on the protection of critical interests and therefore, ADs are a valuable concept. Ultimately any approach that ignores our right to make autonomous decisions sits uncomfortably. Disregarding one's ability to rationalise and determine what happens to their body is a concerning thought especially in regard to medical procedures.[31] Part of what makes us human is our ability to rationalise and come to a decision about treatment. [32] An individual's autonomy (right to self-determination) is "a well established principle" [33] because all competent individuals have the ability to rationalise and choose the plan for their life.[34] Ignoring this ability to rationalise

[24] Dresser "Life, Death and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law", above n 23, at 380-81.
[25] Sam McMullan "Advance Directives" New Zealand Family Law Journal (2012) 6 NZFLJ No 12 at 2.
[26] D. Parfit "Personal Identity" (1971) 80 The Philosophical Review 3 at 20.
[27] McMullan, above n 25, at 2.
[28] Ibid.
[29] Parfit, above n 26, at 7-8; and Shaw, above n 20, at 272-270.
[30] Shaw, above n 20, at 272-270.
[31] Alastair Campbell "Dependency Revisited: the limits of autonomy in medical ethics" in Margaret Brazier and Mary Lobjoit (eds) *Protecting the Vulnerable; Autonomy and Consent in Healthcare* (Routledge, New York, 1991) at 102.
[32] A. Buchanan, "Advance Directives and the Personal Identity Problem" (1988) 17 Philosophy and Public Affairs 277 at 277; and Campbell "Dependency Revisited: the limits of autonomy in medical ethics", above n 31, at 102.
[33] Maclean "Advance Directives, Future Selves and Decision Making", above n 5, at 291.
[34] Buchanan, above n 32, at 277; and *Re MB (Medical Treatment)* [1997] 2 FLR 426 at 432.

means imposing on patients what others believe to be best.[35] Autonomy is important in the construction of individual identity and the effective expression of one's own convictions. Although experiential interests are significant, self-determination and autonomy should be paramount. Therefore expressions of autonomy are best understood as a reflection of our critical interests. This dissertation presupposes that the philosophical position as described by Dworkin is the correct position to have in contemplation when addressing consent and ADs in medical law.

2. The legal requirement of consent:

Determining what is meant by autonomy is crucial as "the entire law of consent is premised on the dominance of patient autonomy."[36] Obtaining consent allows us to rely on a patient's assessment of what will make them happy, rather than trying to guess this.[37] Autonomy and self-determination are the ethically important values that the law of consent aims to protect.[38]

Notably the test for consent differs depending on whether it is a matter of civil or criminal liability. As usually there is a reasonable care undertaken and a reasonable belief of consent removes criminal liability, concerns that come before the court generally involve civil liability.[39] Questions of civil liability usually involve issues of capacity and "informed consent." Currently the law requires medical practitioners to have obtained "informed consent" before providing treatment.[40] Technically if a patient has capacity they can refuse consent for whatever reasons they see fit.[41] Issues of consent are dealt with under the Health and Disability Act 1994 and The Code of

[35] Robert Young "Informed consent and patient autonomy" in Helga Kuhse and Peter Singer *A Companion to Bioethics* (Blackwell Publishing, Massachusetts 1998) 441 at 442.
[36] Dworkin "Medical Law and Ethics in the Post-Autonomy Age", above n 17, at 727.
[37] Young, above n 35, at 442.
[38] Ibid; and James F. Childress "A principle based approach" in Helga Kuhse and Peter Singer *A Companion to Bioethics* (Blackwell Publishing, Massachusetts 1998) 61 at 64.
[39] *Smith v Auckland Hospital Board* [1964] NZLR 241 at 252; It is established that in order to avoid criminal liability, consent must be to an intervention of the same physical scope and the same nature as that which has occurred, namely it has to be of the same nature and quality. Section 61(1) of the Crimes Act 1961 also provides protection from criminal responsibility where consent has been given and reasonable care and skill has been undertaken.
[40] Health and Disability Commissioner Regulations, Schedule 1, cl 2, Right 7(1); and Health and Disability Act, Section 20(1)(a).
[41] *St George Healthcare NHS Trust v S* [1998] 3 WLR 936, at 937; *HE v A Hospital NSW Trust & AE (by her litigation friend the official solicitor)* [2003] EWHC 1017 (Fam). This case affirmed the paramount status of self-determination. The right of refusal encapsulates the principle of self-determination, which is so paramount that it persists even where the refusal of treatment is life-threating or repugnant to societal views

Rights legislation.[42] Consent is required by virtue of right 7(1) of the Code of Patient Rights[43] and it imposes more "stringent requirements" than what is required to avoid criminal liability.[44] For consent to be legally valid one must have the capacity to understand the nature of treatment and its alternatives before making a decision about how to proceed.[45] There "is no all-purpose test for capacity to give or refuse consent"[46] and the level of capacity required will vary depending on the specific treatment and the specific circumstances.[47]

3. The right of refusal:

Implicit in the right to consent to treatment is the right to refuse medical treatment. Pursuant to section 11 of the New Zealand Bill of Rights Act 1990 all individuals have the right to refuse medical treatment.[48] This fundamental right of refusal is further safeguarded in Right 7 of the Health and Disability Commissioner (Code of Health and Disability Services Consumers Rights) Regulations 1996 (Code of Rights).[49] Specifically Right 7 (7), states, "Every consumer has the right to refuse services and withdraw consent to services."[50] This right of refusal (right 7) is the foundation for both CRs and ADs.

B: Contemporaneous Refusal (CR):

A CR made with capacity will be legally binding on health practitioners.[51] There is a presumption in favour of capacity; however this is rebuttable and is often questioned

[42] Health and Disability Commissioner Regulations. In New Zealand a person's rights to autonomy are established in the Code of Health and Disability Services Consumers' Rights (the Code), which is contained in the Schedule to the Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996.
[43] Schedule 1, cl 2, Right 7(1) "Services may be provided to a consumer only if that consumer makes an informed choice an gives informed consent, except where any enactment, or the common law, or any other provision of this code provides otherwise."
[44] PDG Skegg, Capacity to Consent to Treatment" in Peter Skegg and Ron Paterson *Health Law in New Zealand* (Thomson Reuters New Zealand Ltd, Wellington, 2015) 213 at 200.
[45] *Re C (Adult: Refusal of Medical Treatment)* [1994] I WLR 290 at 292
[46] Skegg "Capacity to Consent to Treatment", above n 44, at 216.
[47] Ibid, At 221. The graver the possible consequences are the higher the standard of capacity that will be required.
[48] New Zealand Bill of Rights Act 1990, s 11, "Everyone has the right to refuse to undergo any medical treatment."
[49] Health and Disability Commissioner Regulations, Schedule 1, cl 2, Right 7.
[50] Schedule 1, cl 2, Right 7 (7).
[51] *St George Healthcare NHS Trust v* S, above n 41, at 937; and *VC v NC* [2015] NZHC 2014, [2015] NZFLR 892 at [13], "medical treatment cannot be imposed on a competent person without their informed consent or some other legal justification."

where the refusal conflicts with the medical advice.[52] In cases where capacity is challenged; it must be established one has the ability "(1) to take in and retain treatment information (2) to believe it and (3) to weigh that information, balancing the risks and needs."[53] Right 6 provides some guidance on the considerations that individuals must contemplate, including consideration of all the options available, expected risks, possible side effects, benefits and cost of each option.[54] Fundamentally capacity is an individual's ability to understand the likely consequences of treatment (both proposed and alternative treatments), and come to a well-balanced determination about the matter. The question is "whether at the time he had a capacity which was commensurate with the gravity of the decision which he purported to make."[55] Generally the more serious the decision and the graver the possible consequences, the greater the level of understanding and capacity will be necessary.[56]

1. The English Approach:

The English cases of *Re C*[57] and *Re T*[58] established the principle requirements for capacity. Notably that one has adequately understood, retained, believed, and weighed up the relevant treatment information when making his decision to refuse.[59] *Re C* involved a schizophrenic patient suffering from a gangrenous foot, who against medical advice was refusing amputation.[60] In this case Thorpe J was satisfied C's schizophrenia did not diminish his general capacity.[61] He still understood "the nature, purpose and effects of the treatment advised and consequently his right of self-

[52] *Re C*, above n 45, at 292; and *St George Healthcare,* above n 41, at 937.
[53] At 292. Affirmed in *NHS Trust v T (Adult Patient: Refusal of Medical Treatment)* [2004] EWHC 1279 (Fam) at [53].
[54] Health and Disability Commissioner Regulations, Schedule 1, cl 2, Right 6(1) "Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive, including – (a) An explanation of his or her condition; and (b) An explanation of the options available, including an assessment of the expected risks, side effects, benefits, and costs of each option; and (c) Advice of the estimated time within which the services will be provided; and (d) Notification of any proposed participation in teaching or research, including whether the research requires and has received ethical approval; and (e) Any other information required by legal, professional, ethical, and other relevant standards; and (f) The results of tests; and (g) The results of procedures."
[55] *Re T* (Adult: Refusal of Medical Treatment) [1992] 3 WLR 782 at 113.
[56] Skegg, "Capacity to consent to treatment", above n 44, at 221.
[57] *(Adult: Refusal of Medical Treatment)* [1994] I WLR 290
[58] (Adult: Refusal of Medical Treatment) [1992] 3 WLR 782.
[59] *Re C*, above n 45, at 295.
[60] At 290.
[61] At 290.

determination had not been displaced."[62] Despite C's delusions his refusal was unfaltering and crucially was made despite knowing it could lead to his death.[63] The second case of *Re T* involved a 34 week pregnant woman (Jehovah's Witness) who was refusing a blood transfusion. [64] Initially the refusal was made under the belief her condition would not be life threating, however following the still birth of her child and her serious health deterioration the blood transfusion became necessary for survival.[65] On appeal it was held she did not have the requisite capacity; as Lord Donaldson identified various factors had diminished her capacity, specifically:[66]

> "T.'s mental and physical state when she signed the form, the pressure exerted on her by her mother and the misleading response to her inquiry as to alternative treatment, meant her refusal was not effective and the doctors were justified in treating her on the principle of necessity."

2. The New Zealand approach

New Zealand also identifies the right to refuse belongs to every competent person.[67] The cases of *R v M* [68] and *VC v NC* [69] show an acceptance of the English approach; specifically a person must have processed the information provided and used it to come to a decision about the matter.[70] Where capacity is challenged one's ability to refuse treatment will need to be explored. The case of *R v M* involved the treatment of a pregnant patient with a severe schizophrenic illness who was refusing a caesarean section.[71] Although she appeared to be capable of a logical approach; and had understood some of the risk involved, she was incapable of acknowledging the effect her mental disorder might have on her decision.[72] This was problematic because her mental disorder affected her ability to understand, foresee and evaluate the

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[62] *Re C*, above n 45, at 290.
[63] At 293.
[64] *Re T*, above n 55.
[65] At 95.
[66] At 96.
[67] *VC v NC*, above n 51, at [13]; and *Re B (Adult: Refusal of Medical Treatment)* [2002] EWHC 249 (Fam), [2002] 2 All ER 449 at [22] to [27]; and *R (on the application of Nicklinson and another) v Ministry of Justice* [2014] UKSC 38, [2015] AC 657 at [23] and [26].
[68] [2005] NZFLR 1095 (FC).
[69] [2015] NZHC 2014, [2015] NZFLR 892.
[70] *R v M* [2005] NZFLR 1095 (FC) at [28]
[71] At [1] & [9].
[72] At [9].

consequences of her decision.[73] Her inability to appreciate the risk of harm to her child and herself meant she did not have the requisite capacity.[74] The case of *VC v NC* involved treatment of alcohol dependency and abuse issues. The court determined that treatment should be imposed where "a person's dependency has seriously impaired his or her capacity to make choices about ongoing substance use and personal welfare."[75]

It is clear that where there is an impaired ability to make choices, namely to retain information and undertake a balanced decision making process, one will not be found to have sufficient capacity. Although the law specifies a presumption in favour of capacity, one's capacity is often challenged and rigorously tested when a refusal is irrational or at odds with the advice of the medical profession. When a refusal can result in death it is understandable why doctors wish to carefully assess a patient's capacity. Practitioners aim to save lives, and when a refusal contradicts this goal they want to be sure the decision has not been made lightly.[76]

C: Advance Directives (ADs):

An AD as per Clause 4 includes "written or oral directives; (a) by which a consumer makes a choice about possible future health care procedures; and (b) that is intended to be effective only when he or she is not competent."[77] As set out in Right 7(5) "every consumer may use an advance directive in accordance with the common law."[78] With few legal restrictions in legislation or common law the acceptance of ADs is largely permissive, unless prima facie something negates its authority.[79] In New Zealand there is a scarcity of case law regarding ADs as problems are dealt with

[73] *R v M*, above n 70, At [28]
[74] At [31]
[75] *VC v NC*, above n 51, at [14].
[76] *Re C,* above n 45; *Re T,* above n 55; *St Georges Healthcare,* above n 41. The Law in relation to consent advocates that one is presumed to have capacity unless it can be proved otherwise. this presumption in favour of capacity is also mentioned in legislation; namely right 7 of the Code of Patients rights.
[77] Health and Disability Commissioner Regulation, Schedule 1, cl 4.
[78] Schedule 1, cl 2.
[79] PDG Skegg "Justifications for Treatment without consent" in Peter Skegg and Ron Paterson *Health Law in New Zealand* (Thomson Reuters New Zealand Ltd, Wellington, 2015) 287 at 292; see also *HE v A Hospital NSW Trust & AE,* above n 41, at [43].

by the Disability Commissioner not the Courts.[80] However given the similarities between the New Zealand approach and the English approach, it is helpful to seek guidance from the wealth of cases at English Common Law. Thus the English approach will also be considered in an attempt to supplement the understanding of ADs.

1. The general approach and a general concern:

The New Zealand case *11HC00512 (Fairview Care Ltd)* outlined the prevailing approach of ADs; namely that for ADs to be binding they need to be completed by a competent consumer and activated only when that same consumer looses capacity.[81] Again like the English approach a person is presumed competent unless there is contrary evidence.[82] The Fairview Case involved the patient Mrs A, who had a history of extreme weight loss. The focus was mainly on inadequate care however there was marginal exploration of her capacity revealing a similar approach to the English approach.[83] Notably her capacity was assessed in terms of her condition and the effect this had on her ability to process the relevant information.[84] Although not much is gained from this case one concern highlighted was the insufficient knowledge healthcare providers have regarding ADs. The main observation in this case was that Fairview Care was extremely unsure of ADs, their effect and how they worked.[85] The recommendation was a refresher course to ensure such problems did not occur again.[86] This suggested that the current approach in New Zealand is far too general.

2. The need for specific contemplation:

The recent case against the Nelson Marlborough District Health Board (NMDHB) provides a deeper analysis of ADs and what is necessary for them to be binding. The

[80] Two possible conclusions can be drawn from deficient case law either there is a largely permissive acceptance of AD or there is a lack of use of ADs and therefore a lack challenges surfacing.
[81] *11HDC00512* [2010] Health and Disability Commissioner Decision at [120].
[82] At [64] & [120]. This case highlighted that there was no evidence that indicated she lacked the capacity to either make or communicate decisions regarding her care and welfare and therefore prima facie she had the capacity to make such a refusal.
[83] At [65].
[84] *Re AK (Medical Treatment: Consent)* [2001] 1 FLR; This case evaluated whether the patient had the requisite capacity to understand not only the development of the condition but also the consequences of refusing treatment. In the case of *Re AK* because he was fully aware of the progression of the condition and he was already experiencing its effect he was found to have the capacity to make an informed decision and his condition did not diminish this capacity.
[85] *11HDC00512*, above n 81, at [122] & [123].
[86] At [122] & [123].

case involved a patient who refused to consent to the use of blood or blood products.[87] The problem in this case was that the refusal was based on a low risk of needing a blood transfusion.[88] However actually the blood transfusion became essential to saving her life.[89] The commissioner observed that there is the need for a specific contemplation; namely the circumstances must have been reasonably in contemplation when the AD was made.[90] The English approach in *W Healthcare NHS Trust v T* identified the a similar concern; notably whether the circumstances that have occurred have manifested what the patient had contemplated; and further the AD was intended to apply in this situation.[91] As emphasised in both these cases for an AD to be binding it needs to be evident that the situation now occurring was in contemplation when the individual created the AD.

3 The threshold of acceptability:

Both the New Zealand and English approaches have the same reluctance to accept an AD where there are noticeable doubts regarding its encapsulation of one's autonomous views.[92] The cases of *Re AK* and *W Healthcare NHS Trust v T* provide some guidance on when an AD will be binding. *Re AK* involved a patient with a motor neuron disease (a degenerative condition) that would eventually result in his death.[93] AK was sufficiently informed about the progression of his disease and he understood its irreversible nature.[94] The AD in this case was held to be binding for two reasons. Firstly it was found that he possessed the competence to make the well-informed decision, having considered all the information relevant to treatment, treatment alternatives and his prognosis.[95] Secondly the instructions he gave to doctors about when the refusal should be implemented were extremely clear.[96] AK's refusal is a perfect example of a binding AD because there was little doubt about its application due to the certainty of his medical prognosis and proximity of the AD's implementation.

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[87] *11HDC00531* [2014] Health and Disability Commissioner Decision at [19]; Permission was sought to override this refusal.
[88] At [177].
[89] At [5].
[90] At [52], [168] & [180].
[91] *W Healthcare NHS Trust v T (Adult Patient: refusal of Medical Treatment)* [2004] EWCA Civ 1324.
[92] At [12], see also *Re B,* above n 67, and *11HDC00531,* above n 87.
[93] *Re AK,* above n 84, at 130.
[94] At 131
[95] At 131 & 136
[96] At 132.

At the other end of the spectrum the case of *W Healthcare NHS Trust v T* demonstrates the opposite. Where statements are too vague, and one cannot be sure they were made in contemplation of the current circumstances the AD will not be binding.[97] Although New Zealand seems to have followed the English in adopting a requirement of specific contemplation, exactly what this threshold is remains underdeveloped. The limited guidance we have is found in the case against NMDHB, which states that the situation now occurring must have been reasonably contemplated when refusal of treatment was given in advance.[98] The approach seems to be that where doubts arise and uncertainty cannot easily be resolved, the preference falls in favour of life-preserving medical treatment.[99] As the majority of cases will fall somewhere in the middle of *Re AK* and *W Healthcare NHS Trust v T* it is crucial that a clear line is drawn, so practitioners know what will be specific enough to be binding.

D: A comparison of the requirement of "Informed Refusal":

Although both CRs and ADs aim to protect individual autonomy they require slightly different legal standards of "informed refusal." Both refusals require consideration of the same things however the level of specificity (detail) required is substantially different. A legally binding CR appears to demand a more specific understanding (of both the treatment and the consequences) than what is required for a legally binding AD.

1. Contemporaneous Refusals: "Informed Refusal"

For a CR to be binding it is essential that the individual gave that refusal following a full understanding of the specific treatment and the consequences of refusing that treatment.[100] Further their refusal must be based on this comprehensive knowledge of treatment and it must have followed an evaluative decision-making process.[101] As the situation is contemporaneous the individual is capable of such a full and detailed understanding. One has access to all the relevant information such as the options

[97] *W Healthcare NHS Trust v T,* above n 90, [12].
[98] *11HDC00531*, above n 87, at [52], [168] & [180].
[99] *W Healthcare NHS Trust v T,* above n 91, at 950. Also see *HE v A Hospital NSW Trust & AE,* above n 41, at [49]; Where Justice Munby that where ones life is at stake "the evidence must be scrutinised with especial care."
[100] *Re T*, above n 55, at 115.
[101] *Re C,* above n 45; at 292. Affirmed in *NHS Trust v T,* above n 53, at [53].

available, expected risks and possible side effects, so naturally it should be considered when making their decisions.[102] Further even with a presumption in favour of capacity, it is evident that it is often challenged. Irrationality of the decision alone will not invalidate the refusal, however it does suggests the need for scrupulous assessment and careful evaluation of the refusal.[103] This evaluation requires a series of considerations and if the consequences are life threating then substantial evidence is necessary to confirm one's capacity and consequently their informed refusal.[104]

Therefore a CR can be quashed if one is found not to have capacity or that a relevant piece of information was not considered when the patient made their decision.[105] Access to and consideration of all the relevant information is crucial. Only if all the relevant information has been considered and balanced will an informed contemporaneous refusal exist and be legally binding.[106]

2. Advance Directives: "Informed Refusal"

ADs in comparison are generally binding unless prima facie something questions it representation of one's autonomous views.[107] Although an AD that lacks specificity will often not binding; there is not the same requirement to have considered all the relevant information with such a high degree of specificity. Rather it just has to been shown that the current situation was likely to have been in the patient's contemplation when they made the AD.[108] As ADs are made in anticipation of future events, the information that should be considered is not so readily available. Although one can anticipate the future generally, it is not feasible to consider the circumstances as comprehensively as if they were happening tomorrow. The problem with ADs is an

[102] Health and Disability Commissioner Regulation, Schedule 1, cl 2, Right 6(1) "Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive, including – (a) An explanation of his or her condition; and (b) An explanation of the options available, including an assessment of the expected risks, side effects, benefits, and costs of each option; and (c) Advice of the estimated time within which the services will be provided; and (d) Notification of any proposed participation in teaching or research, including whether the research requires and has received ethical approval; and (e) Any other information required by legal, professional, ethical, and other relevant standards; and (f) The results of tests; and (g) The results of procedures."
[103] Maclean "Advance Directives, Future Selves and Decision Making", above n 5, at 292; and Re C, above n 45, at 290; and *Airedale NHS Trust v. Bland*, above n 16, at 860 per Lord Keith.
[104] Skegg "Capacity to Consent to Treatment", above n 44, at 221.
[105] *Re T*, above n 55, at 115.
[106] At 115.
[107] Skegg "Justifications for Treatment without consent", above n 79, at 292.
[108] Shaw, above n 20, at 272.

inability to firstly have access to all the relevant information and secondly to fully understand that information.[109] It is highly unlikely that one will be able to predict the future with the degree of certainty necessary to access to all the relevant information. Further it is too burdensome to require someone to consider all the possible scenarios in the same amount of detail as a person would consider one immediate scenario.[110] Therefore with ADs there is a softening of this strict requirement of "informed refusal" partially because it is impossible to consider all the future situations, but also because such a strict requirement might defeat the purpose of ADs.

3. Individual autonomy: a justification for the lower legal standard of "informed refusal":

The benefit of ADs is their ability to protect one's personal autonomy and human dignity during periods of incapacitation.[111] The central idea is others are incapable of making a better decision for a patient, than the decision an individual previously made (before their incapacity).[112] Autonomy is paramount because "patients know their own interests better than their doctors."[113] Autonomy is highly valued as "respecting it leads to the best results for the patient."[114] Best interest or surrogate decision makers only begin to scratch the surface of one's critical interest and thus are insufficient to appropriately safeguard their autonomy.[115] Thus when an individual looses capacity we should rely on their prior critical interests (encapsulated in an AD) rather than attempting to decide for them. No one can fully put themselves in the shoes of that patient in those particular circumstances and we cannot experience these states on behalf of someone else.[116] Thus we are incapable of formulating a better decision.[117] A decision made by the patient with capacity in anticipation of a future

[109] Shaw, above n 20, at 272.
[110] Ibid, at 272-273.
[111] McMullan, above n 25, at 5. McMullan explains that a right to choose is "a reflection of an individual's right to the inviolability of the self. It recognises a person's inherent right to dignity and bodily integrity."
[112] Nancy M P King *Making Sense of Advance Directives* (Georgetown University Press, Washington DC, 1996) at 4.
[113] Shaw, above n 20, at 272-273.
[114] Ibid, at 273.
[115] Maclean "Advance Directives, Future Selves and Decision Making", above n 5, at 291.
[116] King, above n 112, at 4.
[117] Ibid .

event is always going to be better than a decision made later by someone else.[118] Autonomy is important because it allows us to "construct our own identity"[119] and preserve our right to self-determination.[120] It allows the expression of "one's own character, values, commitments and convictions"[121] in this case in respect to decisions regarding treatment. The ability to refuse treatment is extremely significant especially when it comes to invasive or potentially degrading treatments.[122] Consequentially the protection of autonomy should not be lost simply because the patient has lost the capacity to make such refusals known. What separates people from objects is their capacity to reason and decide the rules and standards of our lives.[123] Therefore it is crucial that we are offered protection "from unwanted virtually futile medical interventions that at best may prolong a miserable or meaningless existence."[124]

When we interact with another person without their consent we are effectively bypassing their capacity to reason. The English case *Re MB*[125] states every person with capacity "has an absolute right to refuse to consent to medical treatment for any reason, rational or irrational, or for no reason at all."[126] This right of refusal is so absolute that it can be upheld even if it leads to one's death.[127] The concept of autonomy provides a strong justification for a favourable and lenient approach in relation to ADs as they "allow patients to exercise their autonomy without having anyone try to second-guess what is in their best interest."[128] The person who will be affected by this decision should be the one making it. If too high a threshold was set then it is unlikely that ADs would be accepted and therefore the purpose of protecting

[118] R. Dworkin *Life's Dominion* (Harper Collins 1993) at 223; where he states "We should respect the decision people make for themselves, even when we regard these decisions as imprudent, because each person generally knows what is in his own best interest better than anyone else."
[119] Maclean "Advance Directives, Future Selves and Decision Making", above n 5, at 294.
[120] Ibid, at 293
[121] Dworkin *Life's Dominion*, above n 118 at 223.
[122] *Smith v Auckland Hospital Board,* above n 39, at 219 per Gresson J; "An individual patient must, in my view, always retain the right to decline operative investigation or treatment however unreasonable or foolish this may appear in the eyes of his medical advisors."
[123] Campbell "Dependency Revisited: the limits of autonomy in medical ethics", above n 31, at 102.
[124] Buchanan, above n 32, at 277.
[125] *Re MB (Medical Treatment),* above n 34, at 432.
[126] At 432; and *Sidaway v. Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital* [1985] A.C. 871 at 904-905; Where it was said the right to self-determination entitles a patient to act in a manner which others might consider, misguided, irrational or absurd.
[127] At 432; and *St George Healthcare,* above n 41, at 937, the court held this right to be so paramount that it justifies refusal of treatment even where that refusal of treatment presents a risk of death both to the patient and further their unborn child.
[128] Shaw, above n 20, at 269.

autonomy would be defeated. It makes sense that the law operates in the lenient way it does; as it allows one's autonomy to survive their incapacity.

E: Conclusion

After examining the current approach of the law in relation to ADs the following conclusions can be made. Firstly the current status of ADs in New Zealand Law is ambiguous with little guidance on what requirements are necessary, and what level of specificity is sufficient to impose a legal obligation on doctors.[129] Secondly although there appears to be a presumption in favour of capacity and acceptance of ADs, where challenges are brought before the court there is a tendency to favour life-saving treatment.[130] Thirdly in order to preserve one's autonomy a much lower level of specificity is required for "informed refusal" in ADs compared to the threshold that is required for CRs.[131] Currently there is not a strict threshold just a requirement that the circumstances that have arisen were those contemplated by the patient. [132]

ADs signalled a radical departure away from the traditional paternalistic approach favouring an inclusive and individual oriented approach.[133] Rather than a system in which doctors decided whether treatment was in the patient's best interests (where life-preserving treatment were favoured) there is now a system requiring communication, full disclosure, and crucially a patient's informed consent.[134] Patients are actively included in discussions and are central to the decision-making process. This change ultimately reflects the desire for greater recognition and protection of individual autonomy. As personal autonomy is encapsulated and protected in the right to refuse treatment, the desire to extend this right of refusal is natural. Without such an extension one's autonomy is effectively defeated by their incapacity. This

[129] The only guidance that is given is found in right 7(5); which states that an Advance Directive may be in accordance with common law.
[130] *W Healthcare NHS Trust v T,* above n 90, at [12].
[131] Shaw "A Direct Advance on Advance Directives", above n 20, at 273
[132] *HE v A Hospital NSW Trust & AE,* above n 91, at [42] Per Justice Munby whether an advance directive will be binding or not "is a question of fact."
[133] Pauline Wareham, Antoinette McCallin and Kate Diesfield "Advance Directives: The New Zealand Context" (2005) 12 Nursing Ethics 349 at 357.
[134] Ron Paterson, Health and Disability Commissioner "Advance Directives, Living Wills and Questions of Competence" (presentation to the NZ Hospitals Association Conference 'Chance or Choice – Staying Motivated in Aged Care', 7 March 1997). Ron Paterson stressed this crucial aspect of health care; namely that patietns were included in discussions and further it was vital that they had a full understanding of the treatment options and their consequences.

helps to explain why there is a lenient approach in favour of ADs. However, this lenient approach can lead to various problems, specifically when we bind our future selves to situations that we cannot adequately foresee. As will become clear the preference to protect our autonomy can sometimes result in the loss of our autonomy, especially if we fail to appreciate the constantly changing and evolving nature of our treatment and personal circumstances.

Chapter II. The Problems with the Law of Advance Directives:

With the shift from a paternalistic approach to one in favour of individual autonomy, the expansion of informed consent to include advance directives (ADs) seemed a logical step forward.[135] As all contemporaneous decisions were "minimally prospective" increasing the time lapse seemed reasonable to better protect individual autonomy.[136] However the increased time lapse between the creation and implementation gave rise to novel problems embedded in the unpredictable nature of the future.[137] ADs face similar problems to CRs (i.e. issues of capacity and undue influence) but due to this prolonged time lapse, they also encounter more troublesome uncertainties. The concern is whether in any circumstances ADs can satisfy the same legal standard of "informed consent" that CRs require, and if they cannot should they be equally binding on doctors.

This chapter will identify and discus the issue of "informed refusal", namely whether this can ever be achieved in the context of ADs. In doing so an evaluation of the following will be undertaken. Firstly the problem of prospective ignorance will be evaluated, assessing our ability to adequately predict the future and the effect this has on informed refusal. Secondly the problem of "radical changes" specifically the effect of changes in personal and treatment circumstances. Such an undertaking is important as if these two uncertainties are not addressed the concern is whether the legal approach should impose the same legal obligations on doctors.

The underlying concern is whether the AD still reflects the autonomy of the person it is being implemented on. Recall autonomy, as advanced by Dworkin, is the idea that an individual has the right to self-determination, namely a right to have one's critical interests observed. An AD aims to encapsulate and protect these critical interests (autonomous wishes) by allowing them to survive the loss of capacity. The purpose of ADs "is for an individual to direct, while still competent, what medical treatment that person does not wish to receive when not competent to otherwise refuse that

[135] Maclean "Advance Directives and the Rocky Waters of Anticipatory Decision-Making", above n 1, at 1-2.
[136] Ibid.
[137] Ibid.

treatment."[138] As such it needs to be certain the AD continues to adequately represent individual autonomy; specifically that if the individual presently had capacity they would also be refusing this treatment under these circumstances.

A: The two classes of uncertainties:

Because ADs encapsulate an individual's autonomous views, a fundamental problem emerges if the AD no longer represents autonomy. Recall individual autonomy (principle of self-determination) is the ability one has to determine their own course of treatment in line with their critical interests (morals and goals). ADs gain their authority from the importance of autonomy as established in the legal requirement of informed consent and informed refusal.[139] "Informed consent" requires the patient to have the requisite capacity to make such a decision;[140] namely capacity to hear, retain, believe and balance treatment information.[141] Also the patient must be adequately "informed" of treatment options. This is particularly problematic for ADs. If one is expected to fully understand the consequences of treatment and come to a well-balanced determination about the matter they must considered all the relevant information. Information is critical to autonomy as it affects our decision-making and our ability to rationalise.[142] Explicitly one's ability to formulate a rational decision is limited by the information they are given. As our decisions are heavily shaped by the information we receive and evaluate, when information is limited so to is the expression of our autonomy. For example a decision regarding treatment is likely to depend on the associated risks and benefits. If this information is not complete (missing a material aspect) or, for some reason incorrect, the respective decision is unlikely to truly reflect our autonomy. The protection of our critical interests and our right to make self-determining decisions has effectively been impaired and debilitated.

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[138] McMullan, above n 25 at 2.
[139] Childress "A principle based approach", above n 38, at 64.
[140] Skegg "Capacity to Consent to Treatment", above n 44, at 221.
[141] *Re C,* above n 45, At 292. Affirmed in *NHS Trust v T (Adult: Refusal of Medical Treatment),* above n 53, at [53]
[142] Campbell "Dependency Revisited: the limits of autonomy in medical ethics", above n 31, at 102.

There are two classes of uncertainties in relation to ADs, namely those that occur at the time of creation (common to both CRs and ADs), and those that occur due to the prolonged time lapse (which applies only to ADs.)

1. Uncertainties arising at time of creation:

As ADs are founded on the same legal concepts as CRs, "issues related to validity of Advance Directives will be similar to those relating to informed consent to services."[143] Therefore problems such as competence, undue influence and questions of informed consent will also be present in ADs.[144] These issues of capacity are appropriately addressed by the incorporation of a decision support model (DSM).[145] The DSM recommends treatment discussions are carried out with a doctor (and potentially a lawyer) before the creation of an AD. During these discussions the doctor is required to make assessments regarding one's mental competence, voluntariness and understanding of consequences.[146] The evaluation of factors such as capacity, undue influence and informed consent at the time of creation, ensure these do not become problematic at the implementation stage. As the DSM largely resolves these uncertainties they will not be the focus of this dissertation. Rather the focus is problems that occur following the creation of the AD that the DSM fails to resolve.

2. Uncertainties that result during the interim period:

Due to this increased time lapse between the creation and implementation of an AD new uncertainty begins to emerge.[147] This is because circumstances are likely to have changed since the creation of an AD, making it difficult to know whether the AD should be applied.[148] The problem results because ADs are based on relevant

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[143] Health and Disability Commissioner "Review of the Act and Code 1999" (2009) http://www.hdc.org.nz/the-act--code/review-of-the-act-and-code-1999##1.0%20OVERVIEW at [2.3].
[144] Ibid, At [2].
[145] Chan Hui Yan "Advance Directives Refusing Treatment: A proposal for New Zealand" in Charles Rickett *New Zealand Universities Law Review* (Vol 23, No 1, Thomson Reuters, 2016) 39 at 48
[146] Ibid. The decision support model invites communications between doctors and patients and if possible lawyers as well to ensure that the AD directive that results is a well-informed refusal that will be binding on doctors. This not recommended to become a mandatory process but one that is optional and if undertaken ensures that an AD is binding on a health profession. This models includes a test for capacity at the time of creation and assessments to ensure it is a decision that is voluntarily made by the patient.
[147] Shaw, above n 20, at 272; and Maclean "Advance Directives, Future Selves and Decision Making", above n 5, at 292.
[148] New Zealand Medical Association "Member Advisor Service Information Sheet", above n 10 at 3; and Shaw, above n 20, at 272.

treatment information (if any) and the patient's attitudes and values at the time of creation.[149] The problem that follows is two fold;

1) Firstly, in some cases one has a limited ability to predict and understand the exact nature and consequences of future treatment.
2) Secondly, various changes can occur following creation, which could jeopardise the authority of an AD. Specifically;
    a) A change in treatment circumstance.
    b) A change in personal circumstances.

These problems are not easily resolved by a DSM and require a different approach. The DSM is focused on problems that occur at the time an AD is created ignoring uncertainties that that could arise after this creation. Requiring discussions with doctors will successfully reduce general issues of consent, as it confirms one has the requisite capacity to make such a decision and is voluntarily doing so. However it only resolves questions of capacity at the time of creation. It fails to appropriately address issues of capacity and informed consent that result from an increased lapse in time. Specifically the DSM does not address problems of prospective ignorance or the possibility of changes in circumstances. Therefore addressing this second type of uncertainty is the focus of this dissertation.

3. The problem these uncertainties create:

The significance of an AD is its ability to be binding on future selves. If we are granted such a wide authority to bind our future selves then naturally the expectation is that the right autonomous views continue to bind us. For example if a Jehovah's Witness created an AD refusing blood transfusions, but subsequently left that faith, it is highly likely the underlying rationale (religious belief) for that refusal is no longer held by the patient.[150] This change in mind effectively invalidates the validity of the AD as upholding it would be contrary to the autonomy of that person. Similarly if the treatment circumstances are radically different than what was anticipated, for example development of a condition that is significantly more painful than anticipated, it is likely if a person had capacity to articulate their decision, they would not refuse treatment. Additionally the anticipation of the future circumstance could have been

[149] New Zealand Medical Association "Member Advisor Service Information Sheet", above n 10 At 3.
[150] *HE v A Hospital NSW Trust*, above n 41, at [13].

wholly inadequate as what has arisen could have been beyond the patient's contemplation when they refused treatment. In these situations it would be illogical to uphold an AD. It needs to be clear that the circumstances that are presently occurring are the same circumstances anticipated by the patient when they created the AD and that there has not been a change in mind or treatment circumstance that effectively renders the AD futile.

B: "Prospective ignorance" The problem with informed refusal:

The first problem that results from this increased time lapse is this idea of prospective ignorance. Namely, "the impossibility of predicting exactly what the future would be like means that any advance decision must be one made in ignorance."[151]

1. The requirement of informed consent:

Currently the common law requires informed consent; namely the individual must have considered and evaluated all the relevant information material to the refusal before coming to a balanced decision on the matter.[152] The purpose of gaining informed consent is to ensure that the patient knows what they are consenting to or alternatively what they are refusing to consent to. This is even more important in the context of ADs as they have the ability to bind our future selves indefinitely.[153] However, the common law does not impose any additional requirements for anticipatory refusal effectively treating them the same as CRs. The assumption being that anticipatory refusal is principally the same act.[154] Furthermore, there appears to be a lower standard of "informed decision" for ADs. Where challenges to capacity are made for CRs the standard of consideration (of relevant information) is relatively high.[155] In comparison the standard required for a valid AD is significantly lower.[156]

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[151] Maclean "Advance Directives, Future Selves and Decision Making", above n 5, at 292.
[152] *Re C,* above n 45; at 292. Affirmed in *NHS Trust v T,* above n 53, at [53].
[153] Shaw, above n 20, at 273. The famous saying of information is power rings true here. The access to information is the crucial aspect of consent and when it comes to ADs too often there is a lack of information available to patients about the treatment and the future circumstances. Without the appropriate information it is hard to be sure that they were fully informed to the extent they were capable of making an informed refusal of consent.
[154] Maclean "Advance Directives, Future Selves and Decision Making", above n 5, at 291.
[155] *Re C,* above n 45; at 292*;* It must be determined that where a refusal of medical treatment contradicts medical advice that the patient has the abiltity to "(1) take in and retain treatment information (2) to believe it and (3) to weigh that information, balancing the risks and needs."
[156] Shaw, above n 20, at 273.

As even contemporaneous refusal are somewhat prospective the common law does not view the increased passage of time as changing the nature of the refusal.[157] However this increased time lapse challenges the likelihood of an AD being an "informed" decision. This is problematic as there is "an assumption that an advance directive must be informed in order to be valid."[158] Even if it can be found that a patient has the requisite capacity to make a refusal and has done voluntarily, their refusal must also be informed.[159]

2. The problem with Advance Directives being too prospective:

For a decision to be fully informed the person is required to have contemplated all the relevant information material to the specific treatment. As ADs are prospective they are often made without a specific treatment in mind thus contemplation of all the relevant information is difficult.[160] As CRs are made in relation to a specific treatment, in a specific circumstances the individual has access to all the relevant information and can assess that information in the context of their current experiences and state of mind. In contrast**,** ADs are made in the abstract and patients are attempting to anticipate and then assess these future circumstance. Often not all the relevant information is available and further there is an inability to fully understand and appreciate that information.[161] It is challenging enough to consider with sufficient detail an immediate situation,[162] let alone "predict and account for every relevant future healthcare scenario."[163]

As it is too burdensome to consider all the possible future circumstances it is often the case that "the competent person had insufficient information about their future condition."[164] When we make decisions without specific knowledge of the future and without experiencing conditions, it is difficult to claim the decision was informed.[165]

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[157] Maclean "Advance Directives, Future Selves and Decision Making", above n 5, at 291.
[158] McMullan "Advance Directives New Zealand", above n 25, at 5.
[159] Shaw, above n 20, at 272.
[160] Ibid.
[161] Ibid.
[162] Thomas, above n 1, at 233; where she states "At the time of making a directive, a person cannot be expected to take into account all of the factors, including personal circumstances and changes in medical technology, which may be relevant at some future time."
[163] New Zealand Medical Association "Member Advisor Service Information Sheet", above n 10, at 3.
[164] Shaw, above n 20, at 272. This was described to be the case for lots of Dementia patients because they could not adequately predict they would be happy in their state of Dementia or not.
[165] Ibid.

Ultimately when decisions are made in the abstract there is a lack appreciation regarding the experience of the condition and the treatment they are refusing.[166] Therefore there is essentially an inability to know how they would want to proceed when those circumstances arise.

Given the evolving nature of medicine and complexity of treatment decisions, there is a degree of risk involved in creating an AD.[167] The ability to bind our future selves by prospectively ignorant and largely uninformed decisions is concerning.[168] If we are capable of binding our future selves then we should be held to the same standards required for normal refusals.[169] ADs can only preserve one's autonomy and be self-regarding if decisions are informed.

3. The possibility of an Informed Advance Directive:

As patients are able to give informed and binding CRs where information is limited or they close their ears to information, the requirement of informed refusal may not be so problematic.[170] "The fact that a person may refuse treatment without receiving all relevant information reflects the reality of life."[171] Even though information is crucial in making informed decisions not every piece of information will radically impact our decisions. This is apparent as the duty of disclosure placed on doctors [172] requires disclosure only of risks that the patient "would likely attach significance to."[173] Therefore an AD should not require complete knowledge of future circumstances but just knowledge of significant aspects of the treatment they are refusing and the circumstances they will likely be refusing it in. *Harman v Director of proceedings*[174] conceded that the nature of waiver in New Zealand is uncertain; specifically it is unclear whether a patient has the ability to refuse to hear details necessary for

[166] Shaw, above n 20, at 272-3.
[167] New Zealand Medical Association "Member Advisor Service Information Sheet", above n 10, at 1.
[168] Shaw, above n 20, at 273.
[169] Ibid, at 273. He further elaborates saying "The point is that an advance director must meet the same standard of information and understanding as is normal- but this standard indeed requires more information at the time of writing the directive, because the patient is required to consider many different scenarios rather than her immediate one, which is normally all that is necessary when refusing or consenting to treatment."
[170] McMullan, above n 25, at 5.
[171] Ibid.
[172] *Canterbury v Spence* (1972) 464 F 2d 772; at [19]; and, *Rogers v Whitaker* (1992) 175 CLR 479.
[173] At [19]. Reaffirmed in *Rogers v Whitaker, above n 38*.
[174] [2009] CIV 2007-404-003732 (HC).

informed consent.[175] However the weight of authority suggests one cannot waive the right to be informed and surgeons should insist "on patients listening to sufficient details at least where major surgery carries a high risk."[176]

After considering this duty of disclosure it is reasonable to infer that, ADs should not be upheld where information material to the treatment was not adequately considered. This is because it would be excessively burdensome to require the medical profession to provide the same level of information about a condition as that required for CRs.[177] Rather a duty to disclose significantly material information is more reasonable. Specifically following *Rogers v Whitaker* [178] the standard should require contemplation of information considered to be significant by a reasonable person in the patient's circumstances.

4. Re AK: an example of an informed refusal:

Following this specific knowledge requirement it is logical that ADs should only apply to reasonably anticipated treatments and reasonably anticipated circumstances. For example in cases like *Re AK* the terminal nature of his disease and the certainty of medical prognosis meant that he had access to all the relevant information necessary to make an informed decision.[179] Therefore when AK made a refusal he not only had the capacity to do so but also had access to all the relevant information thus the decision was clearly informed.[180] ADs are most useful in situations where implementation was proximate and circumstances relatively certain.[181] This would include cases of terminal illness, permanent vegetative states, or cases where the prospect of recovery is low.[182] This is because there is often certainty of autonomy in such cases. It is likely an individual is already experiencing symptoms and therefore has an understanding of how it will progress. It also means the ADs can be

[175] *Harman v Director of proceedings*, above n 40, at [85].
[176] At [85]. It is clear that AD can be treated as something that also carries a greater risk since they are often used to refuse life-preserving treatment.
[177] McMullan , above n 25, at 6.
[178] (1992) 175 CLR 479.
[179] *Re AK, above n 84, at 130*.
[180] At 129.
[181] New Zealand Medical Association "Member Advisor Service Information Sheet", above n 10, at 3-4.
[182] Ibid, at 3-4.

specifically drafted in anticipation of this inventible consequence, eliminating a large amount of the uncertainty.

In cases where the appropriate information was not considered or not contemplated with a great degree of detail, there is unlikely to be an informed refusal and a valid AD.[183] In *W Healthcare NHS Trust v T* it was held that there was not sufficient evidence that she understood the nature of her choice or the unpleasantness of death by starvation[184]. Statements such as "did not want to be kept alive" and she "would never be a burden to the girls" were too vague to indicate what KH had meant in terms of her future treatment.[185] This case is an example where information that would be considered by most to be significant and material was not considered. Namely the unpleasantness of starvation was not contemplated.[186] There was a significant lack of understanding and appreciation of the treatment being refused and the effect this refusal would have. If the AD were to be binding, KH would need to have considered this material information. As no such consideration was undertaken upholding the refusal could not be found to be upholding an autonomous decision.

If we accept a person has the ability in some situations to adequately predict future circumstances and evaluate with sufficient detail how they would want to be treated (thus have a valid advance directive) applicability can still be questioned. This problem of anticipatory informed refusal is further complicated by the possibility of a radical change in either treatment circumstance, or personal circumstance. Even if an AD was validly created, there is the possibility that subsequent to its creation the person has had a radical change in either treatment or personal circumstances that renders the AD unrepresentative of their autonomy.[187]

C: The Problem of a "Radical Change" in treatment circumstances.

"The main difficulty lies in determining whether the anticipatory refusal of consent in question has this effect, in the circumstances that have occurred."[188] With the

[183] *W Healthcare NHS Trust v T,* above n 90,at [21].
[184] At [21].
[185] At [8].
[186] At [21].
[187] *HE v A Hospital NSW Trust, above n 41,* at [43].
[188] Skegg "Justifications for Treatment without consent", above n 79, at 291.

increased time lapse between creation and implementation the possibility of changes in treatment circumstances are dramatically increased.[189] Importantly changes in treatment circumstance challenge the ADs' validity namely whether they continue to represent that individual's autonomy.

1. The Two types of change in treatment circumstance:

Change in treatment circumstances can occur in two different situations. Most commonly a change occurs when the development of the condition is significantly different from that anticipated and contemplated during the creation of the AD. This can be because the condition itself has developed in way that was not expected,[190] the patient has developed another condition, or, the treatment of the condition has lead to further complications. A change in treatment circumstance also occurs where medical science advances offer treatment that would be radically different form that which was contemplated. Treatment options may become available that yield better results or offer a less invasive procedure. A change in treatment circumstance refers to changes that occur in this interim period, which if they had been contemplated at the time of creation would have lead to different instructions.[191] Where the development of the condition or the advancement of treatment alternatives it radically different the AD should be deemed invalid. Otherwise the patient is bound by an out-dated AD.

2. The problem with a change in treatment circumstance:

The case against Nelson Marlborough District Health Board (NMDHB)[192] provides a clear example of a change in treatment circumstance. In this case at the time the refusal was made the assessed risk of needing a blood transfusion was low, specifically a blood transfusion would not likely be essential for survival.[193] However following various complications with surgery, the blood transfusion was necessary to save her life.[194] This circumstance was radically different from that anticipated when

[189] New Zealand Medical Association "Member Advisor Service Information Sheet", above n 10, at 1.
[190] For example the condition has developed in such a way that is extremely intolerable or perhaps more tolerable that alters the validity of the AD.
[191] *HE v A Hospital NSW Trust*, above n 41,at [43]. Where it said that an AD may become invalid following a change in treatment circumstance "it may be said that the patient executed the advance directive because he was suffering from an illness which has since been cured; it may be said that medical science has now moved on."
[192] *11HDC00531,* above n 87.
[193] *A*t [177].
[194] At [5].

the refusal was considered and the AD made. The problem with upholding an AD where there has been a change in treatment circumstance is related to informed consent. In the NMDHB case the change in circumstance, meant the AD would be invalid because one could not be sure that the patient had understood all the consequences of her directive (in particular the risk of permanent disability or death.)[195] This problem also appeared in *W Healthcare NHS Trust v T* case, which echoes similar concerns. The concern is whether the circumstances that have occurred where those contemplated by the patient, and therefore the refusal was intended to apply this present situation.[196] The AD in *Re AK* was valid mainly due it's sufficiently specific and proximate to its implementation.[197] As the time lapse was short the possibility of a change in treatment circumstance was greatly reduced.[198]

The problem is not the change in treatment circumstance itself but rather the effect these changes have. Where the circumstances contemplated are radically different from what has occurred it is hard to be sure the refusal is meant to apply. This is problematic firstly because it questionable whether there has been an informed decision, and secondly hard to say that the AD continues to reflect an individual's autonomy. This casts doubt as to whether earlier views (ADs) should be ignored.[199] If a specified treatment has developed in a way that is less invasive or renders better results a patient would be more likely to consent to that treatment. Upholding an AD in these circumstance would effectively condemn the patient to miss out on benefit of these medical advances.[200] Alternatively the patient might be experiencing a radically different development of their condition than was anticipated, or, perhaps the development of a second condition. These developments could be relatively painful without treatment, and if the patient had been aware of this possibility when they had capacity they would not have made a determination to refrain from treatment. In circumstances where treatment is different to such a radical extent as described above, upholding the AD would be irrational and potentially even barbaric. It would be

[195] *11HDC00531,* above n 87, at [177] &[179]
[196] *W Healthcare NHS Trust v T,* above n 91, at [21].
[197] *Re AK,* above n 84, The case of *Re AK* is a somewhat gold standard for Advance directives due it similarities with a CRs. The certainty of condition and its effect in the future meant an informed decision could be made. Furthermore as its creation and implementation were so proximate it meant that it would not be effected by doubts raised by changes in circumstances.
[198] At 129.
[199] Law Commission No 231. *Mental Incapacity HMSO,* 1995.
[200] McMullan, above n 25, at 5

contrary to the individual's autonomy as it is highly likely that given the nature of these changes the individual's decision would be radically different.

D: The Problem of a Radical Change in Personal Circumstance:

Not only is medicine a constantly evolving practice, but individuals and their personal circumstance are continuously changing as well.[201] It "may be alleged that the patient who no longer professes the faith which underlay the advance directive"[202], or, that a person has married or had children and "now finds himself with more compelling reasons to choose to live even a severely disadvantaged life."[203] This prolonged time lapse makes it hard to be certain that there has not been a change in personal circumstances, which could affect the AD's validity. As humans are not static in their lifestyle or beliefs ADs are extremely susceptible to a change in personal circumstance. As individuals grow their values and perception of life often changes.[204] As Dresser explains, people often "adjust to the changing natural and social circumstances that characterise a person's life."[205]

1. The difficult task of anticipating your future autonomy:

It is extremely difficult to anticipate all future circumstances and how we are going to feel in these particular circumstances. How we respond to different situations and circumstances will be hugely affected by the views, morals and beliefs that we hold at that time. These critical interests and values shape the lives we lead and the decision we make. Dworkin defines critical interests as those that "reflect the person's autonomously determined goals and life-plan."[206] They are values, morals and interests such as religious beliefs and career goals, which will influence how we will wish to proceed in the case of treatment. What is important to note is that these are subject to change, and crucially if these do change, so to does the underlying rationale for our decision.

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[201] New Zealand Medical Association "Member Advisor Service Information Sheet", above n 10, at 1.
[202] *HE v A Hospital NSW Trust,* above n 41, at [43]; and Thomas, above n 1, at 233.
[203] At [43].
[204] Thomas, above n 1, at 233.
[205] Dresser, 'Dworkin on Dementia: Elegant Theory, Questionable Policy' in H. Kuhse and P. Singer (eds.) *Bioethics: An Anthology* (Blackwell Publishers Ltd. 1999) at 312.
[206] Maclean "Advance Directives, Future Selves and Decision Making", above n 5, at 295.

HE v A Hospital NSW Trust highlights one example of this concern; namely the effect marriage and children will have.[207] Having such significantly important people in your life is highly likely to alter what you are willing to tolerate (especially where children are dependent on you).[208] Consider a situation where a person's fear of invasive surgeries caused them at the age of 25 (when they were single) to make an AD refusing all invasive treatments with a low success rate. When they come (unconscious) into hospital and require invasive heart surgery with a 30% success rate the AD is much more likely to reflect that individual's autonomy if the person is now only 26 and still single. However serious doubts arise regarding autonomy if they are 30 and married with two children as it is likely their underlying rationale (critical interests) for refusing treatment has changed. If they have married and had children, it is more likely the underlying rationale for refusing treatment (fear of invasive treatments) has been surpassed by an underlying desire to be there for their family. In this second situation upholding the AD would be contrary to the autonomy of the person.

2. A change in mind:

The most common example of a change in personal circumstance is that of change of mind. As one grows, beliefs and opinions are constantly being shaped and altered. [209] This creates serious doubts regarding the ability ADs have to encapsulate and preserve our current autonomous views. Implicit in the idea of autonomy is the ability to rationally make a decision in line with their morals, values and experiences. When decisions are made prospectively the ability to formulate a rational decision is limited, especially when one's mind and ultimately their life plan is subject to constant revision.[210]

The case of *HE v A Hospital NSW Trust* provides a good example of a change in mind. This case considers a change in religion. The AD (refusal of blood transfusion) was created while the patient was a Jehovah's Witness, however by the time it was

[207] *HE v A Hospital NSW Trust,* above n 41, at [43].
[208] At [43].
[209] Maclean "Advance Directives, Future Selves and Decision Making", above n 5, at 302. Where he states "Over time the self gradually evolves and changes, gaining new memories ad beliefs, losing old beliefs and forgetting old memories" "give that there are several possible entitled associated with a single human life, choosing the relevant one has to be a valued judgment."
[210] Young, above n 35, at 441.

implemented she had left the Jehovah's Witness faith.[211] Her justification for her AD was that "being one of Jehovah's Witnesses with firm religious convictions have resolutely decided to obey the Bible command "Keep abstaining … from blood."[212] Her father brought a claim requesting the AD was ignored on the basis that she since December 2002 she had rejected her faith as a Jehovah's Witness.[213] It was argued, "the consent forms signed by AE had predated her change of faith and as such, should not be relied on."[214] Furthermore she had stated when she was admitted to hospital, "she did not want to die."[215] This case found that if AE had been conscious she would "have consented to a blood transfusion without any hesitation."[216] This case was an example of a change in personal circumstance that had the effect of invalidating an AD. The courts stated:[217]

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

The question in this case was not whether the AD was valid to begin with, but rather did the AD have "continuing validity and applicability."[218] It was obvious through the wording of the AD and external evidence (presented by her father) that the AD was founded "entirely on AE's faith as a Jehovah's Witness."[219] Therefore the court determined "that it cannot have survived her deliberate, implemented, decision to abandon that faith and to revert to being a Muslim."[220]

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[211] *HE v A Hospital NSW Trust*, above n 41.
[212] At [12].
[213] At [13]. Evidence for this was provided namely (i) that she was betrothed to be married to a Turkish Man, and a condition of the marriage was she would revert back to Muslim faith. (ii) Furthermore she had not attended any of the Jehovah's Witness meetings/congregations and services, which she used to attend twice weekly. (iv) Prior to her loosing consciousness there was no mention of the AD or refusal to consent to a blood transfusion.
[214] At [13](iii).
[215] At [13] (vi).
[216] At [13].
[217] At [24].
[218] At [25].
[219] At [49].
[220] At [49].

Changes in personal circumstances can also be much more simple; consider the following example of a retired lecturer; who is coming in and out of capacity. [221] The patient creates an AD refusing life-sustaining treatment, specifically in cases like that of pneumonia. However four months after creating the AD he is invited to give a speech in two months in Australia. The prospect of giving the speech brings the lecturer joy and honour and he wishes to attend. Unfortunately before he is able to give the speech he arrives at hospital with pneumonia. The AD clearly refuses treatment in these circumstances. The problem here is that since the invitation to speak; his personal circumstances have changed such that if he had capacity he would consent to treatment. Ultimately his autonomous views are no longer appropriately represented or protected by the AD. His critical interests and life plan currently revolves around giving this lecture. His AD was limited by this lack of foresight. It is easy to imagine situations like these arise frequently. For example grandparents might want to attend an award ceremony or such event of their grandchildren, which might conflict with an AD that refuses treatment.

3. The problem with a change in personal circumstances:

Similar to changes in treatment circumstances, changes in personal circumstances result because decisions are made prospectively. Any substantial period of time lapse before implementation amplifies the uncertainty of individual autonomy prevailing. The greater the passage of time the greater the uncertainty that the AD still encapsulates the correct (most recent) autonomous views of the patient.[222] If the circumstances that have arisen are radically different form the circumstances in which the AD was created, it is unlikely that it appropriately reflects that individual's autonomy. In those circumstances following the AD might be binding the future-self incorrectly. The argument is that the "patient who has changed his mind is not to be condemned to death because pen and ink are not readily to hand."[223]

[221] Example from a conversation with Dr Barry Snow (Neurologist at Auckland Hospital) at July 5th 2016.
[222] Skegg, "Capacity to consent to treatment", above n 44, at 221; and *Re AK*, above n 84.
[223] *HE v A Hospital NSW Trust*, above n 41 at [41]. Again this case reiterated that where there is doubt that doubt falls in favour of life-preserving action.

E: Conclusion:

The most problematic difference between CRs and ADs is the increased time lapse between an ADs creation and its implementation. It leads to an inability to appropriately anticipate the future (prospective ignorance) and an increased likelihood of subsequent radical changes. Therefore a cautious approach as suggested by Ron Paterson is the best way to ensure that ADs continue to uphold their underlying purpose (specifically the protection of individual autonomy.) Namely;[224]

> "In the absence of clear evidence that the patient had anticipated these very circumstances, was adequately informed, had not changed her mind, a cautious approach seems sensible and is likely to judged sympathetically in the event of future inquires."

In circumstances where the implementation of AD is challenged, for fear it fails to reflect their autonomous wishes, caution needs to be taken. This is particularly important in circumstances where there has been a change in circumstances or there are doubts that the circumstances which have arisen, were not those contemplated by the patient. In these circumstances an evaluation needs to undertaken to ascertain whether implementing an AD would be contrary to the autonomy of the person.

Unlike a CR where there is the ability to clarify, confirm or revoke refusals easily at various stages, an AD cannot be clarified or confirmed. This amplifies the effect problems such as "prospective ignorance" and "change in circumstances" can have. Therefore evidence must be used to establish whether that prior refusal of treatment was not only made in contemplation of the events now occurring (namely it was an informed refusal), but also that the refusal continues to reflect the autonomous wishes of the person. The greater the time lapse between the creation of an AD and its implement the harder this task is, and the less certain it tends to become.[225]

The problems of prospective ignorance and change in circumstance contradict the very purpose of an AD. Following an AD that is contrary to autonomy is "to abandon vulnerable patients to their fate simply because they are incapable of correcting an earlier decision, which, with the benefit of the passage of time, now appears

[224] Ron Paterson "Medico- Legal Knowledge in New Zealand" (2009) 112 (1300) NZMJ 5 at 5.
[225] Skegg, "Capacity to consent to treatment", above n 44, at 221; and *Re AK*, above n 84.

mistaken." [226] Apprehension occurs with ADs because we are either unable to adequately predict the future with sufficient certainty, or, that changes have occurred during the time lapse that undermine the prior treatment refusal decision. There needs to be some kind of confirmation that the circumstances that have arisen were adequately considered by the patient. Further assurance is required that there has not been a change in mind or circumstance that means upholding the AD would be contrary to one's individual autonomy. These specific problems (prospective ignorance and change in circumstances) frequently occur and acknowledging this in a prospective manner by stricter regulation is like to yield better certainty than the current retrospective analysis. Certainty of autonomy needs to be clear, namely is needs to be clear that the autonomous views and critical interest that the AD purports to uphold actually reflect the correct (most recent) critical interest and thus are a rational self-determination. If problems such as prospective ignorance and change in circumstance are readily acknowledge and appropriately managed by stricter regulation then there will be less hesitancy to implement a compliant AD.

[226] Maclean "Advance Directives, Future Selves and Decision Making", above n 5, at 292.

Chapter III. Recommendations:

Currently a large proportion of ADs are challenged or ignored by the medical profession for lack certainty and specificity).[227] Doctors are reluctant to implement an AD where they are unsure it actually represents one's autonomous wishes.[228] Problems of prospective ignorance and change in circumstance create uncertainty that the AD accurately represents one's autonomy. This "uncertainty of autonomy" results in hesitancy amongst doctors to apply an AD. Unlike CRs (that will be binding if capacity is found) even if and AD was created by someone with the capacity, the problem of prospective ignorance or a change in circumstance; could still render the AD invalid. Both these problems occur due to this prolong time lapse and cause the resulting AD to be contrary to one's autonomy. Thus this problem is specific to AD and thus requires a new approach.

This chapter will propose various recommendations that will work to reduce this uncertainty of autonomy. Firstly the "best interest test" will be thoroughly examined in an effort to highlight that imposing stricter regulations will not compromise individual autonomy. Secondly three regulatory recommendations will be proposed that aim to reduce the uncertainty of autonomy. These recommendations will increase the legal standard of ADs to ensure specificity and thus impose a legal obligation on doctors. Stricter regulations and safeguards will lessen how prospective ignorance and change in circumstance manifest in this uncertainty of autonomy. Regulation will diminish both doubts of autonomy, and the current reluctant approach by ensuring compliant ADs are binding on doctors.

A: The Best Interest Test:

The best interest test is applied when a person is found incapable of making an informed choice or giving informed consent. It requires doctors to evaluate and give

[227] PDG Skegg "Omission to Prolong life" in Peter Skegg and Ron Paterson *Health Law in New Zealand* (Thomson Reuters New Zealand Ltd, Wellington, 2015) 653 at 67; and "Health and Disability Commissioner "Review of the Act and Code 1999", above n 143, at 3.2.2.

[228] *HE v A Hospital NSW Trust & AE*, above n 41, at [43]. This case highlighted that where "there is doubt that doubt falls to be resolved in favour of the preservation of life. So if there is doubt the advance directive cannot be relied on the doctor must treat the patient in such a way as his best interest require."

weight to any evidence of the patient's autonomous wishes in determining whether or not treatment is in their best interest.[229]

1. The test under the code:

The test under the Code appears to be a form of the substituted judgment test. Pursuant to Right 7 (4)[230] where a person cannot make an "informed choice or give informed consent"[231] a doctor can only treat where it is in patient's "best interest" and "reasonable steps have been taken to ascertain the views of the consumer."[232] However treatment provided must be "consistent with the informed choice the consumer would make if he or she were competent."[233] This goes further than just considering the evidence of autonomous wishes. It is effectively requiring the healthcare professional to deduce the patient's likely wishes and act accordingly. Such an approach ignores the idea that no one is able to make a decision better than the patient themself.[234] A substituted judgment effectively defeats the aim of ADs by exposing the patient to a decision formulated by someone else.

This causes problems for views encapsulated within an AD. Where an AD fails to be binding, if the views were considered under the code then any decision subsequently made would have to be consistent with these views. This is concerning as usually when we invalidate ADs it is because we doubt their ability to reflect individual autonomy. To then make a decision (using a substituted judgment test) that must be consistent with views (previously doubted to reflect individual's autonomy) seems illogical. Surely the law would not work to impute views that lacked certainty of intention into a substituted judgement test. The only way to resolve this problem and make sense of the law is to read down Right 7(4)(c)(i). Looking to cases such as *Re G* it is clear that this is the approach common law has taken.

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[229] *Airedale NHS Trust v Bland*, above n 16, at 371
[230] Health and Disability Commissioner Regulation, Schedule, cl 2. Right 7(4).
[231] Schedule 1, cl 2. Right 7(4).
[232] Schedule 1, cl 2. Right 7(4)(a)&(b).
[233] Schedule 1, cl 2. Right 7(4)(c)(i) "if the consumer's views have been ascertained, and having regard to those views, the provider believes on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if he or she were competent."
[234] Dworkin, *Life's Dominion,* above n 188, at 223; where he states "We should respect the decision people make for themselves, even when we regard these decisions as imprudent, because each person generally knows what is in his own best interest better than anyone else."

2. The test in practice:

The common law applies the best interest test as established in the English case of *Airedale NHS Trust v Bland*.[235] Namely "whether it is in the best interest of the patient that his life should be prolonged by the continuance of this form of medical treatment or care."[236] In New Zealand a clinician will make a decision "taking into account"[237] and "giving weight to"[238] the patient's best interests considering their probable choice and any evidence of their wishes.[239] *Re G* make it clear that life-sustaining treatment will not be permitted where this would be contrary to the probable views of the patient.[240] *Re G* concerned a patient experiencing serve brain damage with no prospect of recovery.[241] The court adopted the best interest approach and thus gave weight to "the likely wishes of the patient and the views of his family and medical carers."[242] Considering that the nature of his injuries (his quality of life), medical opinion, familial support and the likely wishes of the patient the court determined withdrawal of treatment was in his best interest.[243] This case illustrated the primacy of autonomy implicit in the best interest test and the crucial role patients should play in determining treatment decisions.[244]

3. The test as an alternative to Advance Directives:

It is clear that where an AD fails to be legally binding, doctors will not ignore the views expressed in it. Any evaluation doctors undertake must consider evidence of that patient's autonomy. Doctors will not be able to treat where this conflicts with

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[235] *Airedale NHS Trust v Bland*, above n 16,
[236] At 371.
[237] Health and Disability Commissioner "Advance Directives in Mental Health Care and Treatment (Leaflet)" (2009) <http://www.hdc.org.nz/publications/resources-to-order/leaflets-and-posters-for-download/advance-directives-in-mental-health-care-and-treatment-%28leaflet%29 > at 1.
[238] *Re G* [1996] 2 NZLR 201 (HC) at 203.
[239] Health and Disability Commissioner "Advance Directives in Mental Health Care and Treatment (Leaflet)", above n 237, at 1.
[240] *Re G*, above n 238, at 201.
[241] At 201 & 203. Fraser J describes his condition stating "Mr G, who is now 69 years of age, was severely injured in a motor accident on 31 July 1995 and has been in hospital since. He is totally immobile, is unable to talk or otherwise communicate in any meaningful way and is incontinent of urine and faeces. His CT scans and EEG show severe brain damage. Every effort has been made to rehabilitate him but to no avail. He has remained in the same state and there is no prospect of recovery. He is kept alive by food and fluids through a gastrostomy tube and is provided with all necessary and appropriate medical and nursing care. If his feeding and hydration through the gastrostomy tube were stopped, as is proposed, he would be kept comfortable by nursing staff until he died, which would probably be within about a week during which time he would not be in pain or suffer."
[242] At 203.
[243] At 202.
[244] At 201.

expressions of individual autonomy. Where an AD fails to be binding the expression of autonomy should still be considered. Although the consideration should have regard to the fact something negated the AD authority to be legally binding. As will become clear ADs may fail to impose a duty on doctors for reasons of specificity, however in such cases they may continue to adequately represent an individual's underlying rationale and autonomy and thus should be considered. Where the best interest test is undertaken if there is convincing evidence of autonomy,[245] that evidence must be considered. Where treatment conflicts with expressions of autonomy the current approach favours the recognition and protection of that expression of autonomy. [246] The principle of self-determination is a paramount consideration and the best interest test ensures medical treatment is not imposed where it is clear that if patient were competent they would abstain.

One potential problem with a best interest test is that it could raise the question of which interests should be protected. Recall Dworkin's example of Margo and the tension encountered between critical and experiential interests.[247] If the best interest test aims to protect these critical interests there is no substantial disadvantage if the AD is invalidated, as treatment will still be refused. However if her experiential interests were prioritised then under the best interest test it is likely treatment will be provided. Currently the common law has preferenced the right to self-determination. However as the best interest test is broadly defined and the decision maker can essentially take into account any factors they wish when determining a patient's best interest. The disadvantage being that critical interests are not assessed in isolation like they are with an AD, rather they are balanced against other factors such as, healthcare opinions, familial wishes and a patient's experiential interests.[248] Legally speaking where autonomous wishes are expressed they to be the paramount consideration is to, however other factors can come into consideration.[249] Acting in the best interest of a patient means respecting their autonomy where they cannot articulate this. Imposing treatment where it is clearly contrary to the patient wishes, would be to cut across the principle of self-determination. The best interest test must consider autonomy and

[245] For example evidence such a clearly articulate AD is likely to be compelling.
[246] Thomas, above n 1, at 238.
[247] Shaw, above n 20, at 272-270.
[248] Thomas, above n 1, at 238.
[249] *Re G,* above n 238, at 203.

therefore provides a good alternative for patients that have failed to create a legally binding AD.[250] It is against this backdrop the strict regulatory recommendations in this chapter can be justified.

B: The Introduction of Formalities:

Currently an AD can be made either orally or written[251] which generates great uncertainty in their implementation.[252] Thus the first recommendation is that an AD needs to be executed in writing, witnessed and signed in order to be binding.[253] Such formality would eliminate the uncertainty of autonomy that results from this increased time-lapse forcing creation of ADs to be done in the abstract. If formalities are introduced then the problem of prospective ignorance and change in circumstance could be addressed and diminished. Practically this would allow ADs to impose legally binding obligations on doctors. Imposition of such formal requirements follows the approach adopted in England, Canada and parts of Australia. England introduced the Mental Capacity Act 2005 and in section 25(5) & (6) formal requirements, specifically that an AD (when refusing life-sustaining treatment) needed to be in writing, signed, and witnessed.[254] Similarity in South Australia the Advance Care Directives Act 2013 prescribes for the use of forms when creating an AD.[255]

1. Reducing the problem of change in circumstances:

Imposing formalities can reduce the likelihood of a change in circumstances affecting an AD. Studies have shown that when one has carefully contemplated a decision it is less likely to change.[256] As Justice Munby comments, writing often ensures a

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[250] *Airedale NHS Trust v Bland*, above n 16, at 371. The best interest test currently is not one in which an individual autonomous wishes (and their critical interest) are disregarded as there is a duty for doctors to consider such views

[251] Health and Disability Commissioner Regulations, Schedule 1, cl 4.

[252] Skegg "Omission to Prolong life", above n 228, at 676.

[253] "Health and Disability Commissioner "Review of the Act and Code 1999", above n 143, at 2.3.2; A written requirement was highly recommended.

[254] Mental Capacity Act 2005, s 25(6) states an Advance Directive is only valid if it complies with this subjection namely "(a) it is in writing (b) it is signed by P or by another person in P's presence and by P's direction, (c) the signature is made or acknowledge by P in the presence of a witness, and (d) the witness signs it, or acknowledges his signature, in P's presence."

[255] Advanced Care Directives Act 2013, s 11(5).

[256] Everhart MA, Pearlman RA**.** *Stability of patient preferences regarding life-sustaining treatments*. Chest. 1990; 97:159-64. Danis M, Garrett J, Harris R, Patrick DL. *Stability of choices about life-sustaining treatments*. Ann Intern Med. 1994;120: 567–73.

thorough consideration of the treatment and a fruitful understanding of the consequences of refusal.[257] "It requires individuals to think carefully about their wishes regarding treatment and to translate those wishes into specific instructions."[258] In a study examining the stability of life-sustaining treatment choices it was found that patients with a living will (written) were much less likely to change their mind about treatment that those who did not have a living will (or anything in writing.)[259] The difference was substantial; notably within the two year period of those with a living will only 14% changed their mind compared to 41% of the group that did not have anything in writing.[260] Imposing a formal process will ensure the patient discuses and considers "the realities of death and dying" thus creating a more comprehensive AD.[261] Writing imputes an element of seriousness requiring a greater degree of thought. By forcing an AD to be in writing it would largely exclude barely contemplated off-handed remarks, as it requires a more conscious from the individual than simply stating your wishes.[262]

2. A step towards resolving uncertainty of autonomy:

The benefit of having something in writing is that it aids tremendously in establishing proof of intention.[263] From a practical perspective "it will be easier to prove the existence of an advance directive and it's content if it is in writing."[264] Additionally more detail will likely accompany the resulting ADs, making it clearer what circumstances were in contemplation at the time the AD was created and when the AD was intended to apply. An individual decision is more likely to be stable and the situation appropriately contemplated, if they are forced to create a written AD that

[257] *HE v A Hospital NSW Trust*, above n 41, at [34].
[258] Lindy Willmott "Advance Directives and the promotion of autonomy: A comparative Australian Statutory analysis" (2010) 17 JLM 556 at 586; and Skegg "Omission to Prolong life" ", above n 228, at 676. Where he states, "Informal expression of wishes should be treated with considerable caution. It is not uncommon for people, when well to think and say "were I ever in that condition, I would not want to be kept alive." Yet following an incapacitating stroke (for example), people often view matters very differently. Furthermore, people will express views in great variety of circumstances, so it is not every passing comment that warrant being acted upon at a layer stage."
[259] Danis, Garnett, Harris et al, *Stability of choices about Life-Sustaining Treatments,* above n 256, at 567-573.
[260] Ibid.
[261] Thomas, above n 1, at 235.
[262] *HE v A Hospital NSW Trust*, above n 41, at [34]
[263] McMullan, above n 25, at 4.
[264] Ibid.

clearly explains their wishes.[265] Additionally written ADs will increase the certainty and validity in the eyes of medical practitioners.[266] The formality is particularly important when refusing life-sustaining treatment. New Zealand would benefit from enhanced guidance surrounding ADs and their requirements. Formality is crucial in establishing a much greater certainty of autonomy by eliminating the effect of prospective ignorance and the problem of change in circumstance. If doctors can be more certain that the AD adequately represents an individual's autonomy then they will be less reluctant to implement it.

C: Revocation and the possibility of a Shelf Life:

Currently there is no formal approach for either creation or revocation of ADs[267] making it hard to establish whether an AD has been revoked or is still valid.[268] The uncertainty of autonomy resulting from problems of prospective ignorance and change in circumstance is only amplified by this inability to confirm or clarify one's refusal. As ADs only become enforceable once a patient has lost capacity there is this inability to clarify or confirm that the refusal is still reflective of their autonomy. This second recommendation; (imposition of a shelf life) is aimed at reducing this problem. The imposition of a shelf life would allow an AD to apply for a specified period of time and after which its validity lapses. Where this time period lapses the presumption in favour of validity is rebutted and following *HE v A Hospital NSW Trust* the burden of proof would rest "on those who assert the continuing validity and applicability of the advance directive."[269]

1. Addressing the problem of prospective ignorance

A requirement for revalidation would reduce the time lapse between the creation and implementation of an AD. Importantly this reduces the level of prospective anticipation required ensuring greater certainty in the AD's validity. By decreasing

[265] McMullan "Advance Directives", above n 25, at 4
[266] Ibid.
[267] *HE v A Hospital NSW Trust*, above n 41at [35]; where it is stated "The same principles must, in my judgment, apply to the revocation of an advance directive. If there are no formal requirements for a valid advance directive there can equally be no formal requirements for the revocation of an advance directive. Nor can it make any difference whether the advance directive was itself oral or in writing. An advance directive, whether oral or in writing, may effectively be revoked either orally or in writing."
[268] At [42].
[269] At [42].

the possible time between the circumstances in which the AD is created and the circumstances in which it is likely to be implemented, the level of prospective analysis is decreased. Simply it is much easier to predict where we will be and how we will feel in two years time than trying to determine these things in ten years time. If an AD is required to be reconsidered and revalidated then the decision made will be much less prospective manner with contemplated circumstances being much more proximate. This will better safeguard the certainty of autonomy.

2. Reducing the problem of change in circumstance:

The imposition of a shelf life counters the problems of changes in circumstances by requiring the revalidation of the AD.[270] As most people's ideas change with age; there is a significant a risk that the time has lapse between the creation and implementation of is substantial it will no longer reflect the patient's (most current) autonomous wishes.[271] It could be that advances in treatment mean the earlier AD should be ignored or perhaps that change in personal circumstance such as a change in religion negates the validity of a previously created AD. Whatever the reason the imposition of a shelf life (requiring mandatory review) will help to reduce the likelihood of these changes occurring.

3. The legal effect of a shelf life:

The current approach requires a patient's choices in regard to treatment to be reasonably consistent over time; and this not reflective of real life.[272] A collection of studies found that approximately 85% of patients' preferences are only stable for a period of up to two years.[273] These studies included decisions made by people facing hospitalisation and sometimes life-threatening illnesses.[274] Furthermore following a change in circumstance a person realistically is unlikely to have communicated this change in circumstance to either the family or doctor.[275]

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[270] Shaw, above n 20, at 274.
[271] Thomas, above n 1, at 235-6.
[272] *HE v A Hospital NSW Trust*, above n 41.
[273] Emanuel & Emanuel, *Decisions at the End of Life* (1993) 23 Hastings Centre Rep at 6; and Danis, Garnett, Harris et al, *Stability of choices about Life-Sustaining Treatments*, above 256, at 567-573.
[274] Ibid; at 6.
[275] *Malette v Shulman* (1990) 72 OR (2d) 417; and Thomas, above n 1, at 236. Human are often extremely busy and informing people of wishes when they loose capacity is often a hard discussion to have so it is unlikely they will frequently have these types of informative discussions.

Imposing a shelf life would ensure one is not arbitrarily bound to previous autonomous wishes. Some states in America require renewal such as is found in the California Health and Safety Code,[276] which requires renewal every 5 years. In line with such an approach it would be reasonable to impose a similar shelf life requiring a renewal every two years to ensure the validity of an AD and deter doubts doctors might have in implementing them. It is clear that the imposition of a shelf life is necessary to combat the uncertainty of autonomy. Rather than rendering an AD void when this time lapses, shifting the balance of proof onto those wishing to assert the AD is a good compromise. The law is effectively allowing an individual the right to bind their future selves whilst appropriately limiting the scope of this prospective refusal. It confines one's ability to bind themselves to a future instance that is reasonably proximate and therefore reasonably in contemplation. It does not compromise individual autonomy because in cases of lapses, evidence can still be brought to prove its validity. The legal effect is that compliant ADs will be upheld whilst those causing doubts can be established to be valid by way of compelling evidence.

D: Threshold of specificity:

The final recommendation follows on from the imposition of a shelf life and further targets the manifestation of the problems of prospective ignorance and change in treatment circumstances. The implementation of a threshold of specificity would increase requirements for an informed refusal to a similar level required by CRs. Ut is conceded that one can never adequately predict and consider future circumstances to the extent necessary for decision to be as an informed as a CR;[277] however currently AD are interpreted too widely. AD should only be permitted in circumstances that have clearly been anticipated and where all the relevant information has been available when the decisions was made.[278] It is somewhat contradictory to have such a high standard of informed consent for decisions (refusal of treatment) in the present, but then allow a lower standard of "informed" when individuals are anticipating unpredictable future scenarios.

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[276] The California Health and Safety Code (1992), at para 7189.5
[277] Shaw, above n 20, at 272.
[278] Ibid, at 273.

1. The spectrum of specificity:

In the United Kingdom; case law suggests that that a level of specificity regarding what treatment is being refused is required (*W Healthcare NHS Trust v T*)[279] as well as a level of understanding regarding the outcome is required (*Re AK*).[280] The English case of *Re AK* is perhaps the best example of the level of threshold that should be expected. In this case AK had access to all the relevant information, thus ensuring a comprehensive understanding of his condition, but also his instructions were specific enough so that the doctors knew exactly when to implement the AD (specifically two weeks after he lost the ability to communicate).[281]

An example given by Dr Barry Snow can further help to illustrate the problem of a lower threshold of specificity. Snow presents the idea of a patient who comes into hospital with a tattoo on his chest saying "do not resituate."[282] The doctors initially open his mouth to find a drumstick lodged in his throat. Removing this is an extremely easy fix and not likely to result in any long-term harm for the patient. It is highly unlikely that this situation was the man had in mind when he created this AD (got the tattoo). Rather he probably intended it to apply in a situation such as a cardiac arrest where there is a greater potential for harmful consequences. There is a need to know what was contemplated by the patient when the AD was created and when they intended the AD to come into effect.

By way of analogy an example to consider is consent for posthumous use of tissue (organ donation) under the Human Tissue Act 2008. Under the Human Tissue Act (HTA) the general rule for the use and collection of human tissue is that it is done with informed consent.[283] Informed consent is consent "to that kind of collection or use of the tissue."[284] Explicitly the collection needs to be of the kind and nature

[279] *W Healthcare NHS Trust v T*, above n 91, 4 at [8]. In this case it was held that there was not sufficient evidence that she understood the nature of her choice or the unpleasantness of death by starvation. Statements such as "did not want to be kept alive" and she "would never be a burden to the girls" were too vague to indicate what KH had meant in terms of her future treatment.
[280] *Re AK,* above n 84, at 133.
[281] At 129.
[282] Conversation with Dr Barry Snow, above n 221.
[283] Human Tissue Act 2008, s 19.
[284] Section 9.

anticipated and the kind and nature of use that was consented to. This higher level of specificity is similar to the threshold we experience with CRs. Namely informed consent is consent to the specific collection of organs for the specific purpose of organ donation. This Act requires a lot more than just a vague indication on a driver licence (donor or non-donor) to validate the decision to donate organs. A driver's licence however can act as an indication of a person's wishes arguably in a similar manner to an AD acting as an indicator in the best interest test.

2. The concern and the need for change:

When there is a higher level of informed consent in two similar areas of medical law it is hard to understand why require a different level of understanding for AD. If we require such a great level of consideration for organ donation and CRs how do we require so little for AD.

As Alluded to in *HE v A Hospital NWS Trust* following major changes in one's life such as marriage (or divorce) and children, one's autonomy (underlying rationale) for a decision is likely to be impacted and potentially altered.[285] The type of family arrangements one is party too and the circumstances one experiences significantly effects what is considered tolerable.[286] A similar concern is present and addressed in relation to the revocation of Wills. Under the Wills Act 2007 there was an effort to appropriately account for changes in circumstances such as marriage that the Will had not accounted for.[287] A radical change in circumstances, such as entry of a marriage or civil union, meant the Will was automatically revoked,[288] unless if could be proven the Will was made in contemplation of that marriage or civil union.[289] The concern is that if ADs are not required to be specific then individuals with a vague AD might be arbitrarily bound when it no longer reflects their autonomy. There is a need for precision in ADs as they give a wide authority to bind our future selves. The concern that is common to cases involving ADs is that it is no longer representative of that autonomy. The desire is to give effect to one's autonomy, namely their right to self-

[285] *HE v A Hospital NSW Trust,* above n 41, at [43].
[286] At [43].
[287] Wills Act 2007, ss16 &17.
[288] Section 18(1) "A will is revoked if the will-maker marries or enters a civil union."
[289] Section18(3).

determination. However where there is a lack of contemplation it is hard to ascertain whether the AD would succeed in achieving this.

3. The Threshold Specificity: a firm line:

Recall in *NMDHB* case the Health and Disability Commissioner recommended a specific contemplation requirement; namely the circumstances must have been reasonably in contemplation when the AD was made.[290] The imposition of a specific standard has yet to be determined however it is generally agreed that the standard should require contemplation of all relevant information; namely information considered to be material (significant) by a reasonable person in the patient's circumstances.[291] Such an approach reflects the duty disclosure and the requirements of informed consent as found in *Rogers v Whitaker.* Specifically the duty to disclose relevant information considered significant by a reasonable person in the patient's circumstances. The argument is that "if a patient has a right to make all the appropriate decisions, they must also have a right to all the information necessary for decision-making."[292] As ADs are a form of refusal recognised by the law, it is clear patients have the right to create them. However it must be sure that when they are created they are done so with adequate consideration of the relevant information. For example a consideration of the prognosis of the condition, the options available and the associated risks, side effects and benefits, the results of test, and results of procedures.[293]

In order for an AD to create a legal obligation on doctors it must be found that the refusal was an informed refusal; namely the circumstances that have arisen were

[290] *11HDC00531,* above n 87*,* At [52], [168] & [180].
[291] *Canterbury v Spence*, above n 172, at [19]. Reaffirmed in *Rogers v Whitaker, above n 38*.
[292] Harry Lesser "The Patients Right to Information" in in Margaret Brazier and Mary Lobjoit (eds) *Protecting the Vulnerable; Autonomy and Consent in Healthcare* (Routledge, New York, 1991) at 102.
[293] Right 6(1) highlights the wide range of information that a patient should be provided with stating "Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive, including – (a) An explanation of his or her condition; and (b) An explanation of the options available, including an assessment of the expected risks, side effects, benefits, and costs of each option; and (c) Advice of the estimated time within which the services will be provided; and (d) Notification of any proposed participation in teaching or research, including whether the research requires and has received ethical approval; and (e) Any other information required by legal, professional, ethical, and other relevant standards; and (f) The results of tests; and (g) The results of procedures."

reasonably in the patient's contemplation at the time the AD was created. Such a threshold would be as follows:

(a) The advance refusal must be made in respect of circumstances that a reasonable person in the patient's position could have anticipated and contemplated.

(b) The contemplation of these circumstances must involve consideration of all the information a reasonable person in those specific circumstances would consider to be significant and therefore relevant.

The specificity threshold will not be meet where it is clear that the patient could not have contemplated these circumstances, or, new information has since become available that the patient should have considered. In these situations ADs are stepping outside what the law should recognise as an informed refusal of consent. Where the circumstances occurring fall outside the scope of reasonable contemplation, it is hard to ascertain the patient intended the AD to apply. In these cases the presumption in favour of a binding AD should be rebutted and the individual's wishing to assert that AD needs to provide evidence of its continuing validity.

For the law to bind doctors its needs to be sure that the circumstances were appropriately considered and the AD was meant to apply in this present situation. A greater degree of specificity regarding the implementation of an AD (under what circumstances specifically it should be implemented) must be required. For example not simply that it ought to be implemented when capacity is lost, but further that it is to be implemented when capacity is lost and the specified condition has progressed to a certain specified point. The best way to do this would be to require people to provide their reasons for creating an AD.[294] If people were clear about their reasons for AD then these reasons can be used in situations where the level detail was insufficient to determine whether in the present circumstances the patient intended it to apply.[295]If reasons are given then this can allow for a less specific directions, as it allows the user's reasons to serve as underlying rationale that help to determine

[294] Shaw, above n 20, at 274.
[295] Ibid.

whether the AD should apply.[296] If reason where given and this level of threshold was imposed, it would be reasonable to impose a duty on doctors to uphold compliant ADs. An AD that meets this threshold of specificity would clearly be sufficiently certain, removing any doubts that it does not reflect individual autonomy. If the threshold is not meet, then the best interest test would still consider this views, and further if reasons for the AD were included this would be particular valuable for the purposes of the test.

E: Conclusion:

As the most problematic difference between CRs and ADs is this increased time lapse and thus the correct legal response is to address the problems that arise during this time period. The point of introducing regulatory regimes for ADs is that it will ultimately decrease the effect the problems (such as prospective ignorance and change in treatment circumstance) that occur during this time lapse and thus increase the likelihood that a patient's wishes will be binding on doctors.[297] Introducing legislation will reduce the need for "expensive and distressing judicial procedures" and remove the stress doctors and family members often face regarding terminating treatment decision.[298]

The introduction of formal requirements such as written components, revocation formalities and a shelf life; will reduce a lot of the uncertainty that currently surrounds the implementation of AD. Formality has the benefit of providing a framework that individuals can work within to ensure that their individual autonomy is protected and acts of self-determination regarding medical treatment are binding on doctors.[299] The approach recommended is very similar to the English approach, which often provides New Zealand with good guidance. The fact that so many jurisdictions that New Zealand tends to look to for guidance have implemented similar formalities is a good indication that legislative change is required to fix the uncertainty that is currently accompanying ADs.

[296] Shaw above n 20, at 274.
[297] Thomas, above n 1, at 235.
[298] Ibid.
[299] Ibid.

The imposition of a shelf life and the development of a level of specificity also aim to alleviate the uncertainties that challenge the validity of an AD. A shelf life reduces the level of prospective analysis by reducing the time gap between the circumstances that need to be anticipated and the circumstances they are being anticipated in. This most effectively reduces the problem of prospective ignorance by constraining the level scope of anticipatory refusals to a period of two-years. It also indirectly reduces the likelihood of changes in circumstances occurring. The articulation of a threshold of specificity further resolves issues of prospective ignorance and change in circumstances by ensuring the circumstances that have arisen were reasonably in the patient's contemplation at the time the AD was created. Where it is clear that the patient could not have contemplated these circumstances, or, new information has since become available that the patient should have considered the threshold will not be met.

From a practical point of view these recommendations will ensure firstly that autonomy is appropriately reflected in ADs and secondly that doctors will be bound and thus autonomy adequately protected. The recommendations will likely decrease the number of valid ADs, but it will ensure those that are complaint will be enforced. Those that fail to comply will still help to protect individual autonomy by providing evidence to be considered under the best interest test. Stricter regulation is not only necessary for clarity of ADs and to remove complicating factors that occur during this time lapse, but will also ensure ADs continue to uphold their purpose which is to protect individual autonomy.

Conclusion:

Currently the law provides little guidance or regulation surrounding the use of ADs.[300] In comparison to what is required for CRs there is a largely lenient approach adopted by the court in relation to ADs. This is justified on the ability ADs have to safeguard individual's autonomy during periods of incapacity.[301] As autonomy is so fundamental to ADs a great amount of power is given to their ability to bind our future selves. The problem occurs when circumstances arise in a manner that we did not adequately foresee. In such situations our future selves are bound by out-dated refusals, which have subsequently been surpassed following various changes in this interim period.[302]

ADs are particularly vulnerable due to the increased time lapse between their creation and implementation. This prolong time lapses causes problems of prospective ignorance and change in circumstances which amplify issues regarding the certainty of autonomy (whether ADs encapsulates the current individual's autonomy.) Apprehensions identified with ADs occur because we are either unable to adequately predict the future with sufficient certainty, or we do anticipate the future adequately but subsequent changes have occurred during the time lapse that undermines the prior refusal made. As we are so concerned with protecting individual autonomy we need to ensure the law appropriately address and removes these doubts. Only when the uncertainty is removed will ADs be able to fully achieve their purpose and impose a legally binding duty on doctors. Currently a large proportion of ADs are frequently challenged or ignored by the medical profession on the basis that they lack the requisite force of being certain (specific) and therefore binding.[303] Thus there is a strong need for the law to address and fix these problems.

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[300] Health and Disability Commissioner Regulations, Schedule 1, cl 2, Right 7(5); which states that an Advance Directive may be in accordance with common law.

[301] McMullan, above n 25, at 5. McMullan explains that a right to choose is "a reflection of an individual's right to the inviolability of the self. It recognises a person's inherent right to dignity and bodily integrity."

[302] We don't get this same issue with CRs because ADs unlike CRs experience this time lapse between creation and implementation, which can sometimes be a significant period of time making the AD susceptible to various changes.

[303] Skegg "Omission to Prolong life", above n 228, at 675, See also "Health and Disability Commissioner "Review of the Act and Code 1999", above n 143, at 3.2.2.

Adequate legal regulations for ADs, are crucial for two reasons. Firstly, placing stricter regulations on the requirements for AD will diminish some of the overwhelming uncertainties that accompany ADs. Secondly, it will help to ensure that ADs that comply with these regulations are binding on doctors. At first greater regulation may be feared to reduce the already narrow subset of users, but practically it will give a greater effect to AD and impose a greater obligation on doctors to follow complaint ADs. The biggest hurdle ADs must overcome is the uncertainty of autonomy. With the problem such as prospective ignorance and change in circumstance is it hard to ascertain whether an AD continues to reflect individual autonomy. The imposition of a shelf life and the development of a level of specificity will reduce this by clearly determining when the AD remains valid or not. Stricter regulation will resolve the common fear that instructions might actually be contrary to the patient's individual autonomy thus increasing the likelihood of binding AD. By anticipating and addressing the chance that these now experienced circumstances were not appropriately considered, or a change in circumstances could have occurred the law can safeguard compliant ADs (that do reflect individual autonomy) from these undermining uncertainties.

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