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Refusing Treatment Prior to Becoming Incapacitated: Supported Decision-making as an Approach in Advance Directives

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Abstract

Advance directives (ADs) provide people with the opportunity to express their wishes about treatment preferences prior to becoming incapacitated. While the normative logic behind ADs remain straightforward, as instruments of law they are not always effective because of questions about their validity and applicability. It is on this basis that this article attempts to resolve the legal intricacies on ADs refusing treatment prior to becoming incapacitated. The author advances a thesis in support of a modification of an approach known as supported decision-making to facilitate people in making ADs. This approach pre-empts most of the doubts about an AD's validity. The argument is founded on the presumption that an AD made using the supported decision-making approach provides a higher degree of assurance about the circumstances surrounding the making of ADs, rendering it more likely to be binding on healthcare professionals.

Keywords

advance directives (ADs) – autonomy – supported decision-making – Mental Capacity Act (MCA)

Introduction

On the basis of common law principles, and statutory provisions medical practitioners have a duty of care towards patients.¹ Thus, it is well within the

¹ See generally Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics* (5th ed, Oxford University Press, New York, 2001).

purview of the law that, if the patient lacks capacity, then in the absence of an advance directive, they must be treated in their best interests.² While this functions strictly as a legal duty, along the same rubrics of law, the right of a competent adult to refuse medical treatment, even treatment that keeps one alive, is legally preserved.³ What follows this standard is the legal principle that a medical intervention without any valid informed consent is an offence against that person under the common law and the medical practitioner can be incriminated with battery.⁴

This concept is derived from the common law right of an adult person to self-determination and bodily integrity.⁵ Still, this operates as a default mechanism, and it generally remains the norm, as certain margins of exceptions can be found, via the conduits of an advance directive (AD).⁶ The term “advance directive is most commonly used to refer to the anticipatory refusal of medical treatment.⁷ Thus, in theory, a patient can give an advance directive to outline the treatments they do not wish to receive. This legal concept is similar to the ethical principle of patient autonomy, that a patient has a right to make informed decisions about receiving or refusing medical care.⁸ To put it simply, an AD is a legal document drawn up by individuals when they are well to express their wishes as to their future care and medical treatment, when they are no longer able to make decisions for themselves because of illness or incapacity.

The logical and legal bases are that a medical practitioner is required to act within this AD unless there is evidence that the patient revoked the AD when

² *Re T* [1992] EWCA Civ 18.

³ *Airedale NHS Trust v. Bland* [1993] AC 789; *Re JT (Adult: Refusal of Medical Treatment)* [1998] 1 FLR 48; *Re AK (Medical Treatment: Consent)* [2001] FLR 129; *St George's Healthcare NHS Trust v. S* [1998] 3 WLR 936 (CA).

⁴ See for example the case of *Malette v. Shulman* (1990) 72 OR (2d) 417, where the patient successfully sued the doctor for battery for transfusing blood in contravention of an advance refusal.

⁵ A.I. Tauber, ‘Historical and Philosophical Reflections on Patient Autonomy’, *Health Care Analysis* 9 (2001) 299; L. Willmott, B. White and B. Mathews, ‘Law, Autonomy and Advance Directives’, *Journal of Law and Medicine* (18) 2010 366; I. Kerridge, C. Lowe and C. Stewart (eds.), *Ethics and Law for the Health Professions* (4th ed, The Federation Press, NSW, 2013).

⁶ *Re T* [1992] EWCA Civ 18.

⁷ P. Lack, N. Biller-Andorno and S. Brauer (eds.), *Advance Directives* (Dordrecht, Springer, 2014) p. 75; see also Megan-Jane Johnstone, *Bioethics: A Nursing Perspective* (6th edn., Elsevier, Sydney, 2016) p. 224.

⁸ *Chester v. Afshar* [2004] UKHL 41; *Re MB (Adult, medical treatment)* [1997] 38 BMLR 175 CA; *Re B (Adult, refusal of medical treatment)* [2002] 2 All ER 449; see also AMA Code of Medical Ethics, Opinion 10.01.

still competent. An advance directive does not necessarily apply to all situations, and whether the patient's current condition is covered or still applicable by his directive has to be checked.⁹ This follows the conceptual understanding that when an adult becomes incapacitated he loses the right to decide on his medical care. Thus, the validity of ADS, one aspect of it, somehow depends on the notion of "capacity, which finds its authentic expression in Section 2 of the Mental Capacity Act 2005 (MCA).¹⁰ However, capacity as a concept discussed in empirical literature is not free from theoretical controversies.¹¹ This is generally compounded by the theory of least restrictive intervention, which runs parallel to the conceptual belief that anything done for or on behalf of people without capacity should be the least restrictive, in line with their basic rights and freedoms.¹²

The framework of Section 4(6)(a) of the MCA is explicitly clear on this. The analytical view of this substantive provision plainly states that when determining a person's best interests when that person lacks capacity, any written statement made when they had capacity should be considered. Remarkably, the preparatory work towards the MCA can be drawn upon to dismantle the tenacity of this concept in legal sense. It is significant that the deliberations by the Law Commission provide us with a solid framework in understanding the legal conundrum of capacity. The Commission had advanced a proposition for the British government to accept a "functional approach in determining whether a person has the capacity to make a particular decision.¹³ This approach, which provides a solid legal foundation of capacity focuses on whether the individual is able to make a decision at the time when it has to be made.

In the orthodox sense, ADS were designed to contain enriched content to assist individuals and their appointed agents, families, and physicians to better

9 *W Healthcare NHS Trust v. H and others* [2004] EWCA Civ 1324; *HE v. A Hospital NHS Trust & AE (by her litigation friend the Official Solicitor)* [2003] EWHC 1017 (Fam).

10 Chapter 9, entered into force.

11 See for example, R.J. Leo, 'Competency and the Capacity to Make Treatment Decisions: A Primer for Primary Care Physicians', *J Clin Psychiatry* 1(5) (1999) 131; A. Mogg and A. Bartlett, 'Refusal of treatment in a patient with fluctuating capacity — theory and practice', *The Journal of Forensic Psychiatry & Psychology* 16(1)(2005) 60-69; S. Mukherjee and A. Shah, 'Capacity to consent: issues and controversies', *Hospital Medicine* 62(6) (2013) 351.

12 One of the core principles in the Mental Capacity Act 2005, Part 1.

13 Law Commission, *Mental Incapacity* (London: HMSO, 1995), (Consultation paper no 231.); Lord Chancellor's Department. *Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults: A Consultation Paper* (London: HMSO, 1997); Lord High Chancellor. *Making Decisions: The Government's Proposals for Making Decisions on Behalf of Mentally Incapacitated Adults* (London: The Stationery Office, 1999) (Cmnd 4465.).

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understand and honour their wishes, and this was in response to the increasing sophistication and prevalence of medical technology.¹⁴ The philosophical aspects of an AD are a notion well-founded in the empirical literature. Moreover, the legal system of many civilised countries has been receptive to the idea of AD, except that although an AD is binding under common law, the legal status is often not a settled one under statute law. For instance, in the United States (USA) it has a legal status,¹⁵ while several European jurisdictions, Canada, Australia and Singapore have also granted specific ADs legally binding status in their respective statutes.¹⁶

In fairness and bent on protecting justified expectation, Parliament intended to allow patients to express their wishes before they become incapacitated, and this resulted in the introduction of the MCA in 2005.¹⁷ This statute, which governs the legal field of ADs is applicable in England and Wales. Built around six overriding principles, the MCA gives advance decisions refusing treatment a legally binding status and advance statements of persuasive authority. Prior to the inception of the MCA into the legal landscape of England and Wales, common law jurisprudence had developed gradually in this field, providing some guidance to the legal status of ADs. Common law dictates that

14 J. Childress, 'Dying Patients. Who's in Control?', *Law, Medicine & Health Care* 17(3) (1989) 227-228.

15 Patient Self Determination Act in 1990 (Federal Law); Uniform Health Care Decisions Act 1993; the 50 states in the USA regulate advance directives according to their respective set of laws.

16 Council of Europe, 'Recommendation CM/Rec (2009)11 of the Committee of Ministers to member states on principles continuing powers of attorney and advance directives for incapacity', *Eur J Health Law* 17(2010)205-210; R. Andorno, N. Biller-Andorno and S. Brauer, 'Advance health care directives: towards a coordinated European policy?', *Eur J Health Law* 16 (2009) 207-227; Advance Medical Directives Act 1996 (Sg), Mental Capacity Act 2005 (UK), ss 24-26; Guardianship and Administration Act 1990 (WA); Medical Treatment Act 1994 (ACT); Guardianship and Administration Act 2000 and Powers of Attorney Act 1998 (Qld); Consent to Medical Treatment and Palliative Care Act 1995 (SA); Advance Care Directives Act 2013 (SA); Guardianship and Administration Act 1993 (SA); Medical Treatment Act 1988 (Vic); Advance Personal Planning Act 2013 (NT), Health Care (Consent) and Care Facility (Admission) Act RSBC 1996 c 181; Personal Directives Act 2000 RSA c P-6, Advance Health Care Directives Act 1995 SNL c A-4.1; Personal Directives Act 2005 SNWT c 16; Personal Directives Act 2008 SNSc 8; Consent to Treatment and Health Care Directives Act 1988 PE1 c C-17.2; An Act respecting end-of-life care Bill 2014 (52) c 2 (Quebec); the Health Care Directives and Substitute Health Care Decision Makers Act 1997 S c H-0.001; the Health Care Directives Act 1992 CCSM c H27; Health Care Consent Act 1996 SO c2.

17 Chapter 9, entered into force.

individuals possess autonomy and self-determination, which encompass the right to accept or refuse medical treatment.¹⁸

By its construction, the MCA does not render the legal position of common law legitimately defective, however, it only adds certainty to the cardinal principles of the law. Thus, the common law has now been refined by the MCA, which has clarified the common law principles of rights to bodily integrity and of autonomy of people who are temporarily or permanently incapacitated by accident, disease or some other events. Now, our legal system endorses the principle that all persons are competent to make reasoned decisions unless demonstrated to be otherwise. Therefore, in England and Wales people may make an AD or appoint a proxy under the MCA. This legislation provides a statutory benchmark, a basis for advance decisions to refuse treatment.

Under the aegis of the law, an AD that was made when the patient was mentally competent, acted voluntarily and with an understanding of the nature and consequences of the refusal would be upheld. The MCA also provides that an AD can be overridden if the person is subject to compulsory treatment under the Mental Health Act 1983,¹⁹ and this is generally the problem under the so-called presumption of capacity in section 2(1) of the MCA.

Notably, the statute distinguished legally binding ADs from advance statements, with specific requirements for ADs in sections 24 to 26 that have to be complied with in order to be valid and legally binding.²⁰ As a general matter, the MCA has a companion Code of Practice (COP) aimed at assisting the healthcare practitioners and anyone implementing the law. It provides a number of safeguards to ensure that ADs are not misused, for example, allowing a medical practitioner to exercise an unreasonable clinical judgement to treat patients, if there is uncertainty about the directive.²¹

Within this spirit, the COP has full statutory force, and adds to the guidance in the main MCA, which means that certain people are under a legal duty to have regard to them including people exercising functions relating to the deprivation of liberty safeguards, and people acting as a relevant person's representative²² under the deprivation of liberty safeguards.

18 See for example the affirmation of right to bodily integrity and self-determination in *Schloendorff v. Society of New York Hospital* 105 NE 92 (NY 1914) that was widely endorsed in the Commonwealth jurisdiction.

19 Chapter 20. Part II.

20 Section 25(5) Mental Capacity Act 2005.

21 Under sections 42 and 43.

22 A 'relevant person' is a person who is, or may become, deprived of their liberty in accordance with the deprivation of liberty safeguards.

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As a matter of empirical logic, ADS were advocated as valuable tools to protect the right to make decisions.²³ This notwithstanding, there were critiques about its effectiveness when the person became incapacitated.²⁴ In the narrative several empirical studies and cases have turned on the light about the ineffectiveness of ADS, which are largely attributed to the inability of the persons having to give effect to the ADS, to verify whether the AD still represents the wishes of the person.

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These concerns tie in with questions about its validity, in particular, the theoretical controversy about whether the person was mentally capacitated when it was made, whether the person was acting voluntarily, whether the person knew what the person was refusing, and whether any subsequent changes had occurred that would affect the person's prior wishes.²⁵ There was also the problem of applying the mechanics of ADS itself. The contradiction is that if the contents were vague or imprecise, or fell outside the scope of the AD, the AD would be inapplicable,²⁶ making the law often the refuge of last resort, providing unsatisfactory results.

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23 L. Kutner, 'The Living Will: Coping with the Historical Event of Death', *Baylor L Rev* 27(1975) 39-53 pp. 27, 39; L. Kutner, 'Due Process of Euthanasia: The Living Will: A Proposal', *ND LJ* 44 (1968-1969) 539-554; M.J. Silveira, S.Y. Kim & K.M. Langa, 'Advance directives and outcomes of surrogate decision-making before death', *N Engl J Med* 362 (2010) 1211-1218 (an investigative study which supported the continued use of advance directives in elderly patients who had prepared advance directives received care that was strongly associated with their preferences); N.L. Cantor, 'Advance Directive Instruments for End-of-Life and Health Care Decision Making: Making Advance Directives Meaningful', *Psych Pub Pol and L* 4 (1998) 629-652; D. Shoemaker, 'The Insignificance of Personal Identity for Bioethics', *Bioethics* 24 (2010) 481-489.

24 Some examples are A. Fagerlin and C. Schneider, 'Enough: The Failure of the Living Will', *Hastings Center Report* 34 (2004) 30-42; H.S. Perkins, 'Controlling Death: The False Promise of Advance Directives', *Annals of Intern. Med.* 147 (2007) 51-57; C.J. Ryan, 'Betting your life: an argument against certain advance directives', *JME* 22 (1996) 95-99; C. Hertogh, 'The Misleading Simplicity of Advance Directive', *International Psychogeriatrics* 23 (2011) 511-515; J.A. Devereux, *Australian Medical Law* (Routledge Cavendish, London, 2007) pp. 933-938.

25 For example, *Re T* [1992] EWCA Civ 18; *HE v. A Hospital NHS Trust & AE* [2003] EWHC 1017 (Fam); *NHS Trust v. T (adult patient: refusal of medical treatment)* [2004] EWHC 1279 (Fam); *Re C (refusal of medical treatment)* [1994] 1 WLR 290 (Fam); *Re AK (Adult Patient) (Medical Treatment: Consent)* [2001] 1 FLR 129, [2000] 58 BMLR 151; *HE v. A Hospital NHS Trust & AE* [2003] EWHC 1017 (Fam).

26 For example, the case of *W Healthcare NHS Trust v. H and others* [2004] EWCA Civ 1324.

becoming incapacitated, as an instrument of law an AD is not always going to be effective because of questions about its validity and applicability. These issues give rise to matters of general principle of law, and we learn immediately that key conflicting questions, such as, under what circumstances it was made or whether it still represents the person's wishes remain commonly an unresolved matter.

It is on this basis that this paper attempts to resolve the legal intricacies on advance directives pursuant to refusing treatment prior to becoming incapacitated. The author advances a thesis in support of a modification of an approach known as supported decision-making to facilitate people in making advance directives. This approach pre-empts most of the doubts about the validity of an advance directive, for example the person's mental capacity or understanding at the time the advance directive was made. The argument is founded on the premise that an advance directive made using the supported decision-making approach provides a higher degree of assurance about the circumstances surrounding the making of advance directives, rendering it more likely to be binding on healthcare professionals.

Refusing Treatment Prior to Becoming Incapacitated and the Importance of Getting an AD Right: Case Law Approach

As emerged above, the right of an adult patient to consent to receiving or not to receive medical treatment has long been recognised by common law, the courts and statutes. Many countries have legal provisions supporting the right of adult patients to refuse care and to provide directives about end-of-life care when the patient can no longer make decisions for himself or herself. The US Supreme Court has recognised that the due process clause of the Constitution gives competent adults an interest in refusing unwanted medical treatment.²⁷

The provisions relating to the existence, validity and applicability of advance decisions, and especially those relating to life-sustaining treatment, are some of the most important ones in the MCA. Notwithstanding the legal possibilities, the practical application of ADS can be difficult, and mostly their difficulty can be seen from some disputes brought before the courts to challenge the validity and applicability of the ADS. In other words, the importance of getting an AD right has only been emphasised in a series of cases where ADS' validity were the subject of legal test.

²⁷ Cruzan by Cruzan v. Director, Missouri Department of Health, 497 U.S. 261 [1990].

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The Case of the Patient Whose Feeding Tube Fell Out

*WNHS Trust v. H and others*²⁸ is an example that illustrates a common scenario in oral ADs; two people discussing nonchalantly what they would not want to happen to them when they become too ill or disabled; then one of them fell ill and a decision must be made about treatment withdrawal. There seems to be a prior expression of wishes but how much weight should be given to it? Is it clear enough? Does the person know what it means? These questions will become important when the oral AD is called into implementation.

The patient in question, Ms KH, suffered from multiple sclerosis. She was a resident in a nursing home that provided her with 24-hour care. KH was fully dependent on the nursing home for her survival because her 'bodily functions ha[d] ceased to work'.²⁹ A consultant physician, consultant psychiatrist and KH's family agreed that she was incapable of consenting to treatment.³⁰ She was fed through a feeding tube. When the tube fell out she was hospitalised. The patient's family opposed the reinsertion of the feeding tube. It was then that the hospital applied to the Court to reinsert the feeding tube in her best interest on the basis that KH lacked the capacity to decide.

Exercising its discretion, the Court granted the declaration on the basis that there was no clearly expressed AD refusing treatment from when she had been competent. The Court of Appeal upheld the High Court's decision upon appeal by KH's daughter and brother. This case demonstrates that unless there is a clear and applicable declaration of refusal, then the AD would not bind the doctors.³¹ The Court declined KH's purported wishes because:³²

- (a) the conversations had occurred many years ago, almost certainly all took place before [she] was admitted to the home in 1994;
- (b) none of them dealt specifically with the withdrawal of feeding;
- (c) there were no medically qualified witnesses who had discussed the ramifications of slowly starving to death over a two-to-three-week period with her;
- (d) there is no suggestion adduced from the evidence that [her] alleged comments were the result of a considered and balanced decision taken after full consideration of all relevant matters.

28 *WHealthcare NHS Trust v. H and others* [2004] EWCA Civ 1324.

29 *Ibid.*, 835.

30 *Ibid.*, 836.

31 *Ibid.*, 838.

32 *Ibid.*, 839.

The example above illuminates the importance of the decision-making process in creating ADS. The majority of the courts' concerns in AD disputes³³ focused on four issues: first, whether the patient had mental capacity at the time the AD was made; second, whether the patient had understood the nature and consequences of the refusal, based on the types of information available, third, what the AD meant in the circumstances that had arisen and fourth, whether the AD still represented the patient's wishes.

This sets the foundation to suggest ways to improve the decision-making process in AD so that when it comes to the implementation stage, there is less likelihood of the veracity of the AD being questioned on one of the grounds described above. The supported decision-making approach is an approach that potentially facilitates KH to make ADS that are more likely to be accepted as binding.³⁴ This approach, its application and some limitations will be explored in the following sections.

The Supported Decision-making Approach

There seems to be a lack of universal definition of supported decision-making.³⁵ It has been defined as 'an approach to decision-making that involves providing a person with impaired capacity the support they need to make their own decision'³⁶ or 'a framework within which a person with a disability can be assisted to make valid decisions, [where] [t]he key concepts are empowerment, choice and control'.³⁷ Another conception of supported decision-making is a

33 See for example *Re T* [1992] EWCA Civ 18; *HE v. A Hospital NHS Trust & AE* [2003] EWHC 1017 (Fam); *NHS Trust v. T (adult patient: refusal of medical treatment)* [2004] EWHC 1279 (Fam); *Re C (refusal of medical treatment)* [1994] 1 WLR 290 (Fam); *Re AK (Adult Patient) (Medical Treatment: Consent)* [2001] 1 FLR 129; [2000] 58 BMLR 151.

34 United Nations Convention on the Rights of Persons with Disability. Convention on the Rights of Persons with Disabilities, online at <http://www.un.org/disabilities/default.asp?id=150>, retrieved 11 June 2015.

35 M. McGuire, 'Supported Decision-making forum: Summary report' (Office of the Public Advocate, 24 February 2010) 4; see also Office of the Public Advocate Systems, 'Advocacy, A journey towards autonomy? Supported decision-making in theory and practice: A review of literature' (February 2014) 26; T. Carney, 'Clarifying, Operationalising, and Evaluating Supported Decision Making Models', *Research and Practice in Intellectual and Developmental Disabilities* 1 (2014) 46-50.

36 Victorian Law Reform Commission. Guardianship Final Report, 30 June 2011; 24: xviii.

37 B. Carter, 'Supported decision-making: Background and discussion paper' (Office of the Public Advocate, Melbourne, 2009) p. 9; G. Davidson, 'Supported and Substitute Decision

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series of formal or informal arrangements intended to support a person ‘make and communicate to others decisions about the individual’s life’.³⁸ Supported decision-making is, in its broadest sense, a mechanism providing support to persons requiring assistance in effecting their rights to legal capacity and communicating their wishes.³⁹

A further dimension is added to our conception of whether there is a universal definition or not, the central idea for supported decision-making is helping people achieve the ability to express or decide autonomously with the appropriate support suitable for them, guided by the goal to empower them. Supported decision-making in the context of ADs refers to providing assistance to people in expressing their wishes through ADs, consistent with their beliefs.

The supported decision-making approach was popularised by an international instrument, the *United Nations Convention on the Rights of Persons with Disability (UNCRPD)*, adopted on 13 December 2006 and came into force on 3 May 2008.⁴⁰ The *UNCRPD* is meant to address the human rights of persons with disabilities, encompassing physical and mental disabilities with reference to ways to facilitate or accommodate disabled persons’ social development, exercise and enjoyment of rights, which includes importantly, protecting self-determination.⁴¹

Its goal is broadly based on the premise that disabled persons should not be excluded from deciding for themselves. The vision of the *UNCRPD* is to cultivate a paradigm shift from viewing the disabled as “objects of charities to “subjects with rights.”⁴² In realising this vision, the *UNCRPD* adopted a functional concept for supported decision-making, where the aim is to support

Making under Mental Capacity Legislation: A Review of the International Evidence’, *Knowledge Exchange Seminar Series* (Queens University Belfast and Northern Ireland Assembly) p. 2.

³⁸ *Ibid.*
³⁹ United Nations Convention on the Rights of Persons with Disability. Convention on the Rights of Persons with Disabilities, online at <http://www.un.org/disabilities/default.asp?id=150>, retrieved 11 June 2015.

⁴⁰ *Ibid.*
⁴¹ *Ibid.* Article 1 of the Convention provides that its purpose is “to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity: N. Caivano, ‘Conceptualizing Capacity: Interpreting Canada’s Qualified Ratification of Article 12 of the UN Disability Rights Convention’, *Western Journal of Legal Studies* 4 (2014) 14-23.

⁴² United Nations Convention on the Rights of Persons with Disability. Convention on the Rights of Persons with Disabilities, online at <http://www.un.org/disabilities/default.asp?id=150>, retrieved 11 June 2015.

the person in exercising their autonomy to decide. This functional concept includes, for example, inquiring into the level of support needed by the person to express their wishes.⁴³ This then entails gathering information and explaining the issues impacting the person’s decision-making, interpreting the person’s wishes⁴⁴ and assisting them with communicating their wishes or acting on their instructions to the extent possible.⁴⁵

The broad framework of the *UNCRPD* has been interpreted in the context of law by reference to reforming guardianship laws for persons with disability, acknowledging that every person, including the incapacitated, possess human rights.⁴⁶ Although the *UNCRPD* is a framework that specifically addresses persons with disabilities, Amita Dhanda argued that it ought to be construed in a broader sense as part of the human rights framework which could be applicable to medical and health matters for people with cognitive disability, social care and welfare to personal decisions, guardianship matters and living arrangements for the disabled.⁴⁷ This observation is correct in the sense that it can include people who are incompetent temporarily due to physical or mental disorder. Support can be provided to restore the person’s decision-making capacity. The extent to which support can be effective for severely demented people wishing to make ADS, however, may be put to the test.⁴⁸

It would therefore, appear self-evident, that although recent research on supported decision-making has primarily focused on supporting people with intellectual disability or cognitive disability in expressing their preferences in

43 Australia Law Reform Commission Discussion Paper 81, ‘Equality, Capacity and Disability in Commonwealth Laws’ (May 2014) p. 77.

44 Secretariat for the Convention on the Rights of Persons with Disabilities, United Nations Department of Economic and Social Affairs (*UN-DESA*), *Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and Its Optional Protocol N14 — 2007 from Exclusion to Equality: Realizing the Rights of Persons with Disabilities* (United Nations, New York) 89, 90.

45 M. McGuire, ‘Supported Decision-making forum: Summary report’ (Office of the Public Advocate, 24 February 2010) 4.

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

47 A. Dhanda, ‘Constructing A New Human Rights Lexicon: Convention on the Rights of Persons with Disabilities’, *SUR — Int’l J on Hum Rts* 8 (2008) 44-58.

48 This is also true for people with intellectual disability seeking to express personal preferences. See N. Kohn, J. Blumenthal and A. Campbell, ‘Supported Decision-Making: A Viable Alternative to Guardianship?’, *Penn State Law Review* 117 (2013) 1111-1157, at pp. 1111-1114, 1128; N. Kohn and J. Blumenthal, ‘A critical assessment of supported decision-making for persons aging with intellectual disabilities’, *Disability and Health Journal* 7 (2014) S40-S43.

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decisions affecting their lives,⁴⁹ the central idea of supported decision-making can be equally applicable to competent people who need assistance in making informed decisions. After all, human beings interact and receive support in various forms in their everyday decision-making, in all aspects of their life,⁵⁰ for example, making purchasing or investment decisions, considering which gym membership to subscribe to or clubs to join, or deciding where to relocate. A mentally competent and a physically disabled person can make these decisions. The difference then lies in the nature of the subject matter, the support necessary to effectuate that decision, as well as the ability to change his or her mind after the decisions come into effect. The more complex the subject matter is, the more support is required to facilitate that decision-making process. Supported decision-making requires external positive actions or support person to accommodate the person's needs to achieve the ability to exercise

49 M. Bach and L. Kerzner, 'A New Paradigm for Protecting Autonomy and the Right to Legal Capacity' (Law Commission of Ontario, October 2010); S. Pathare and L. Shields, 'Supported Decision-Making for Persons with Mental Illness: A Review', *Public Health Reviews* 34 (2012) 1-40; Advocacy for Inclusion, 'Supported Decision Making, Legal Capacity and Guardianship: Implementing Article 12 of the Convention on the Rights of Persons with Disabilities in the Australian Capital Territory' (August 2012; Amnesty International, 2011); *Capacity, Supported Decision Making, Advance Directives and Substitute Decision Making: The Right to Equal Recognition Before the Law — Legal Capacity*, Amnesty International Ireland; M. Wallace, Evaluation of the Supported Decision Making Project, Office of the Public Advocate, November 2012; T. Carney, 'Supported Decision-Making for People with Cognitive Impairments: An Australian Perspective?', *Laws* 4 (2015) 37-59; A. Arstein-Kerslake, 'An empowering dependency: exploring support for the exercise of legal capacity', *Scandinavian Journal of Disability Research* 18 (2014) 1-16; J. Craigie, 'A Fine Balance: Reconsidering Patient Autonomy In Light of the UN Convention On The Rights Of Persons With Disabilities', *Bioethics* 29 (2015) 398-405; M. Browning, C. Bigby and J. Douglas, 'Supported Decision Making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice', *Research and Practice in Intellectual and Developmental Disabilities* 1 (2014) 34-45; J. ten Broek, 'The United Nations Convention on the Rights of Persons with Disabilities: Toward a New International Politics of Disability', *Texas Journal on Civil Liberties & Civil Rights* 15 (2009) 33-52; N. Devi, 'Supported Decision-Making and Personal Autonomy for Persons with Intellectual Disabilities: Article 12 of the UN Convention on the Rights of Persons with Disabilities', *Journal of Law, Medicine & Ethics* 41 (2013) 792-806; T. Carney, 'Clarifying, Operationalising, and Evaluating Supported Decision Making Models', *Research and Practice in Intellectual and Developmental Disabilities* 1 (2014) 46-50, at p. 49; N. Kohn, J. Blumenthal and A. Campbell, 'Supported Decision-Making: A Viable Alternative to Guardianship?' *Penn State Law Review* 117 (2013) 1111-1157, at pp. 1113-1114, 1154.

50 A. Arstein-Kerslake, 'An empowering dependency: exploring support for the exercise of legal capacity', *Scandinavian Journal of Disability Research* 18 (2014) 1-16.

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autonomy and realise the right to decide. Human dignity as empowerment is a notion that is consistent with the historical developments of autonomy, in which the control in medical decision-making is shifted from the authoritative hands of doctors, which is paternalistic, towards patients.⁵¹ The next section considers more fully the application of supported decision-making to ADs.

Applying the Supported Decision-making Approach to AD

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From the perspective of people who are currently competent, supported decision-making helps them to anticipate and avoid the sorts of problems that ADs sometimes encounter. For example, although an able-bodied competent person does not face the obstacles of a physically disabled or mentally impaired person in completing a physical or mental task, the person can benefit from consultations with the doctors about treatment refusal risks and options. As such, the disability here does not refer to the person strictly, or at the time the person makes the AD, but to the future when the person has lost competence. The “disability in the context of a competent person refers to the inability to fully anticipate the changes that can potentially occur after making an AD or appreciating the potential risks of a preferred treatment option, thus requiring support in the form of understanding those risks and options. Supported decision-making strives to address this weakness by providing the support necessary to comprehend the complexity of the decision and reducing some practical obstacles towards achieving a person’s expression of autonomous wishes, resulting in a greater likelihood of the AD being legally binding and the person’s wishes being respected.

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This approach thus enables the person to retain the power as the decision-maker,⁵² enhancing rather than diminishing a person’s autonomy.⁵³ Supported decision-making is a more nuanced approach because it recognizes the support needed to achieve that autonomy to make a decision and does not preclude the existence of networks of people in helping the person express his or her preferences (although distinguishing overbearing influence is a fine balancing act). There is no reason why this concept cannot be applied in the

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51 Empowerment is based on the intrinsic human dignity idea, and the freedom entitled to everyone, which respects personal autonomy; see B. Beylveled and R. Brownsword, *Human Dignity in Bioethics and Biolaw* (Oxford University Press, Oxford, 1993).

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52 R. Dinerstein, ‘Implementing Legal Capacity under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making’, *Hum Rts Brief* 19 (2011-2012) 8-12.

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53 A. Dhandu, ‘Constructing A New Human Rights Lexicon: Convention on the Rights of Persons with Disabilities’, *SUR — Int’l J on Hum Rts* 8 (2008) 44-58, at pp. 44, 48 and 50.

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context of people seeking to make a choice about refusing future treatments and necessitating the support given to the people to exercise that choice. The difference lies in the level of disability when the person sought to make a decision.

Some proposals have been made in respect of the supported decision-making model. For example, Leslie Salzman noted four attributes of supported decision-making — the person maintains the legal right to decide despite the appointment of a supporter; the person can freely enter into or decide to terminate the relationship; the person participates actively in making decisions and the decisions arrived at are generally legally binding.⁵⁴ These qualities reflected upon the importance of ensuring that the supported person retains the ultimate right to decide. Additionally, it may be prudent to establish ‘guidelines’ in navigating the relationship between the person who is supported and the network of supporters in the supported decision-making model. Anna Arstein-Kerslake has proposed four principles towards protecting the supported decision-making relationship — respecting the supported person and the supporters as persons with full moral and legal capacity; acknowledging that while there exists an inequality of powers between the two parties, the parties must refrain from exploiting upon such inequality; ascertaining that the supported person is the ultimate decision-maker expressing his or her own genuine preferences and calling for a less intrusive regulation concerning the affairs of the supported person.⁵⁵

Bearing these attributes in mind how does supported decision-making look in the context of ADs? The approach is particularly valuable at the time when the patient is formulating and setting down their wishes. Supported decision-making employed *at the time the AD was made* could address the concerns raised about the patient’s mental capacity and understanding of the consequences of the treatment refusal. In a contemporaneous refusal, capacity, even if not presumed, can be examined simultaneously. This is not possible in an AD. As such, supported decision-making provides the opportunity for a person to be seen or have his or her capacity to be assessed by a doctor, or referred to an appropriate specialist for such assessments. Secondly, the discussions that occur in the consultation include providing relevant information to the person about the treatment refused. Such discussion can enlighten the person about the nature and consequences of their refusal and the possibility that changes

54 L. Salzman, ‘Guardianship for Persons with Mental Illness — A Legal and Appropriate Alternative?’, *St Louis UJ Health L & Pol’y* 4 (2010-2011) 279-329.
55 A. Arstein-Kerslake, ‘An empowering dependency: exploring support for the exercise of legal capacity’, *Scandinavian Journal of Disability Research* 18 (2014) 1-16, at p.12.

in their personal circumstances, that may or may not lead to changes of mind, may occur. Thirdly, the impact of the changes in circumstances should then be emphasised to the patient, that there is a real possibility that these changes in the personal circumstances may eventuate and to appreciate that the AD then needs to cater to these possibilities, or at least to recognise that the AD may afford no opportunity for a change of mind or a reflection of changed circumstances when the person becomes incompetent.

There will be a range of people who will be involved in the process, according to the needs of the particular circumstances, such as healthcare professionals, lawyers, social or mental health workers or specialists. This postulates an involvement of a multidisciplinary team or in certain cases individuals preferred by the patient. Involving a doctor in this process could be helpful because a doctor is in a position to explain to the patient that circumstances may change when the AD is sought to be implemented, or having the benefit of creating an AD that avoids overly vague or general expressions that would be difficult to interpret. The use of a support person at the time of making the AD can be helpful at the time of implementation. For example, family members would be able to confirm the wishes of the respective patients when they were involved in the AD making process. Besides allowing them to have a better understanding of the patients' decisions, they can provide information to questions raised about the personal circumstances of the patients that might be relevant to implementing the AD and whether any subsequent changes have arisen that would affect the AD. Families may be able to help in explaining the information in a way that can be easily understood by the patient, or to provide emotional and psychological support. Fourthly, through the discussion, the person can consider the possibility of nominating a substitute decision-maker or a trusted person to deal with the implementation of the AD in the event of conflict between family members.

There is reason to suggest that supported decision-making may have already been recommended in AD practices. Section 4(4) of the MCA amplified the premise that the person is encouraged to participate fully in the decision-making process, or be provided with such assistance towards improving the capacity to participate in the process. Patients are encouraged to seek support from their doctors and healthcare professionals in making ADs.⁵⁶ For example,

⁵⁶ Some examples include Royal Australasian College of Physicians RACP Submission: Draft Advance Care Directive DIY Kit (March 2014) 2 where the RACP favoured the involvement of doctors and carers in helping patients and families understand and complete AD forms. Other healthcare organisations recommending doctors' involvement include: New Zealand Health and Disability Commissioner. 2009. Advance Directives in Mental

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the Mental Capacity Act Code of Practice recommended seeking a doctor's advice in preparing to make the AD.⁵⁷ Additionally, it recommends people wanting to make ADs to seek advice from doctors, people who are closely involved in their care or organisations that can specifically advise them for particular conditions.⁵⁸ Such discussions should be recorded in the patient's medical records.⁵⁹ Healthcare professionals recognize that making decisions to refuse future treatment have serious implications and patients need the necessary support in expressing their preferences that would govern their treatment when they become incompetent.

Illustrations of the Supported Decision-making Approach to Advance Directives

In this section I revisit the problematic case identified above and consider how supported decision-making earlier in the process might have helped to avoid the problems that arose. Earlier, I identified the case of KH where her AD was declined. This type of AD is made by persons who are healthy but intended their ADs to govern their treatment in case they become incompetent in the future. The problems that occurred with their ADs arose when they were sought to be implemented. The AD was often made some time before the patient became unwell.

KH was the patient whose feeding tube had fallen out. The hospital wanted to reinsert the feeding tube, but her family opposed it. Her family's opposition arose from statements that KH had previously expressed that she would not want to live in her current circumstances. For example, KH's other daughter,

Health Care and Treatment, online at [http://www.hdc.org.nz/publications/resources-to-order/leaflets-and-posters-for-download/advance-directives-in-mental-health-care-and-treatment-\(leaflet\)](http://www.hdc.org.nz/publications/resources-to-order/leaflets-and-posters-for-download/advance-directives-in-mental-health-care-and-treatment-(leaflet)), retrieved 9 June 2016; American Medical Association, 2016, Advance Care Directives, online at <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/about-ethics-group/ethics-resource-center/end-of-life-care/advance-care-directives.page?>, retrieved 9 June 2016; ABA Commission on Law and Aging, 2016, Myths and Facts about Health Care Advance Directives, online at http://www.americanbar.org/content/dam/aba/administrative/law_aging/2011/2011_aging_bk_myths_factshead.authcheckdam.pdf, retrieved 12 March 2016; NZMA Member Advisory Information Sheet, Advance directive: information and sample form, https://www.nzma.org.nz/_data/assets/pdf_file/0016/17008/AdvanceDirectives.pdf, retrieved 8 June 2016; B. Pace, 'Decisions about End-of-Life Care', *JAMA* 284(2000)2550; B. Pace, 'Advance Directives for End-of-Life Medical Decisions', *JAMA* 283(2000)1518.

57 *MCA 2005 Code of Practice* (The Stationery Office, UK, 2007) para. [9.14].
58 Mental Capacity Code of Practice para [9.14].
59 *Ibid.*

T who had cared for her mother before she left for the nursing home, recalled a conversation with her mother while putting her to bed in which her mother said: 'I don't want to be kept alive by machines'.⁶⁰ KH's brother reported that he was doubtful whether KH knew what she was saying.⁶¹ Mrs N, a long-time friend of KH, recalled KH making similar comments to her when they discussed death, and that KH wanted nothing but the best quality of life.⁶² According to Mrs N, KH had repeatedly informed her that she would never be a burden to her daughters if she could not look after herself.⁶³ KH further emphasised that if she failed to recognise her own daughters she would not want to be kept alive.⁶⁴ When KH was first fitted with the feeding tube, T had disagreed with it, an opinion that was consistent with the feelings of the rest of the family members. Despite this evidence, the court ordered the reinsertion of the feeding tube, because there was no clearly expressed AD refusing treatment in her current circumstances. Her previous wishes were expressed in a conversation many years ago prior to her becoming incompetent, but were not addressed to withdrawing feeding. The court did not think that she had appreciated the nature and consequences of the refusal, as a person would if the person had discussed the refusal with a healthcare professional. As a whole, the court was unconvinced that KH knew what she was refusing.

How would the supported decision-making approach help KH? KH knew about her multiple sclerosis diagnosis, but it was not known from the case what information she had about the progression of her disease and the treatment and care she could be given to assist her to avoid her becoming a burden on her family. If KH did not know about the information regarding the progression of her disease, the supported decision-making approach could help her by having multiple sclerosis specialists advise her about what exactly the disease entailed to enable her to prepare for her future care. She could also arrive at an understanding of what stage she was at when she was first diagnosed and how much time she had before she became incompetent. This information would allow her to assess and deliberate on her preferences and what constitutes a burden to her family.

Understanding the disease is only one aspect of being informed about medical prognosis. Having considered the medical situation, what information did she have about the effect that refusing water and food would have on her? At

⁶⁰ *W Healthcare NHS Trust v. H and others* [2004] EWCA Civ 1324 at 836.

⁶¹ *Ibid.*

⁶² *Ibid.*, 837.

⁶³ *Ibid.*

⁶⁴ *Ibid.*

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what point did she anticipate that refusal would become operative? The facts did not reveal that she had been aware of such information, although through her conversation with her close friend and neighbour it was known that she only wanted the best quality of life. In this aspect, information about the effect of refusing water and food are best explained by a medical professional. Supported decision-making could help through consultation with her doctor when she knew about the diagnosis and what treatment or palliative options were available to patients like her. It would be similar to a contemporaneous clinical consultation between a doctor and a patient about treatment options and the effect of choosing one option over the other. She would have made the AD in anticipation of her degeneration due to the multiple sclerosis, and not some refusal based on hypothetical facts or conjectures.

Similarly, where there was doubt about her mental capacity at the time she purportedly expressed her refusal, she could have had her mental capacity assessed by a qualified professional. The capacity assessment relates to whether as multiple sclerosis patient, she understood the nature and consequences of her refusal. Equally, the approach could help KH at the time she made the AD through a doctor's observation of any signs of undue influence when KH expressed her refusal. Where such influence is identified, there is a chance to remove such influence, thereby assisting her to make a valid AD. In a contemporaneous treatment refusal, the decision could be confirmed with the patient simultaneously. However, in an AD, this would mean requiring KH to understand that she would still voluntarily assume the risk of refusing treatment. This approach could also assist KH in terms of anticipating and accommodating subsequent changes in her personal circumstances that would likely impact her decision. For instance, where there are any changes to her medical diagnosis, she could, while competent, make a statement to the effect that her family's evidence would be preferred (although this would be open to whether it would be accepted), or to appoint them as attorneys under a power of attorney or as substitute decision maker. She could also nominate her family or close friend as the support person who would be able to confirm her wishes when her AD is being implemented.

Conclusion

Advance directives provide the opportunity for people to express their wishes regarding their treatment preferences prior to becoming incapacitated, a notion that corresponds with the ethical principle of autonomy. Its application meanwhile is often controversial. Within the scope of this paper, I have attempted

to articulate the principal complexities of creating and implementing advance directives and argued for the introduction of a modified approach to the supported decision-making model employed within the health and disability decision-making framework. The analysis in this paper supports the introduction of the supported decision-making approach in the process of making advance directives. As illustrated in the case above, KH could have created effective ADS using the supported decision-making approach while she was mentally competent. This approach coheres with the principle of self-determination and respect to bodily integrity. It is intended to assist a person in exercising a preference consistent with the person's autonomy. Being supported in the process of making an advance directive strengthened the person's autonomy, rather than being an undermining factor. This concept, as demonstrated above, can be extended to the context of AD. It can assist people who are in the process of making ADS in anticipation of future incapacity. Supported decision-making is most effective when applied in the process of making ADS, where there exists the chance to discuss, document and confirm the person's wishes as well as ensuring the person has the mental capacity to understand the nature and consequences of the refusal. Additionally, the approach can help accommodate the eventuality of potential subsequent changes by introducing some measures at the time the AD is made. While the person is discussing the AD with the doctor, it is important to emphasise the significance of regular review and confirmation of the AD as the person requires or when changes occur that would impact the application of the AD.⁶⁵ The possibility of subsequent changes could be raised with the person when they are making the AD.

The supported decision-making process illuminates the decision-making process in making ADS, and addresses some of the main obstacles which are found in an invalid AD. With appropriate support, the person may be able to better appreciate the risks and options involved in refusing treatment, thereby increasing the possibility of people contemplating making ADS to be better informed about their preferences and circumstances, arriving at better decisions that would be valid and more likely to be binding, compared to an AD that has not been made using the proposed approach. The person has the opportunity to reflect upon and subsequently cater for such eventualities to occur. Supported decision-making is an effective mechanism in addressing some of the main concerns in ADS, before disputes materialise and thus pre-empts questions about the ADS' validity in the decision-making process.

65 For example, in *Re AK (Adult Patient)(Medical Treatment: Consent)* [2001] 1 FLR 129 AK's decision to cease ventilation was revalidated several times as the changes in his circumstances occurred.