Advance Directives Refusing Treatment as an Expression of Autonomy: Do the Courts Practise What They Preach?

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Abstract: The principle of autonomy is at the heart of the right of a competent individual to make an advance directive that refuses life-sustaining medical treatment, and to have that directive complied with by medical professionals. That right is protected by both the common law and, to an extent, by legislation that has been enacted in the United Kingdom and many jurisdictions in Australia. The courts have a critical role in protecting that autonomy, both in those jurisdictions in which the common law continues to operate and in those jurisdictions which are now governed by statute, and in which judicial determinations will need to be made about legislative provisions. The problem explored in this paper is that while the judiciary espouses the importance of autonomy in its judgments, that rhetoric is frequently not reflected in the decisions that are reached. In the United Kingdom and Australia, there is a relatively small number of decisions that consider the validity and applicability of advance directives that refuse life-sustaining medical treatment. This paper critically evaluates all of the publicly available decisions and concludes that there is cause for concern. In some cases, there has been an unprincipled evolution of common law principles, while in others there has been inappropriate adjudication through operational irregularities or failure to apply correct legal principles. Further, some decisions appear to be based on a strained interpretation of the facts of the case. The apparent reluctance of some members of the judiciary to give effect to advance directives that refuse treatment is also evidenced by the language used in the judgments. While the focus of this paper is on common law decisions, reference will also be made to legislation and the extent to which it has addressed some of the problems identified in this paper.

Keywords: medical law, advance directives, autonomy, self-determination, life-sustaining medical treatment, withholding and withdrawing

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I. Introduction

At the end of life, competent adults are frequently required to make difficult decisions about medical treatment that they wish to receive or refuse. In some cases, because of an individual’s life values and goals, he or she may wish to refuse treatment that many others, including that person’s treating team, may wish him or her to undergo. While good medical practice dictates that medical professionals and the patient discuss treatment options and pathways, the decision to accept or refuse treatment offered ultimately rests with the patient. This is so even if the choice is no treatment at all, and that choice results in the patient’s death. While perhaps complicated by issues of proof, at common law the position is the same if a competent adult has made a treatment decision in advance of the medical situation arising, and subsequently loses capacity. That person’s previously communicated treatment decision will prevail, even if those close to the individual or the treating medical professional would prefer a different treatment pathway to be chosen.

From a legal perspective, two important principles are relevant when considering a competent adult’s refusal of life-sustaining medical treatment, whether that refusal is made contemporaneously or in advance. The first principle is that of sanctity of life. In a liberal democracy, the state’s interest in preserving the life of its citizens is reflected in legal doctrine. For this reason, an adult’s request for life-sustaining treatment to be withdrawn or withheld will be closely scrutinized. The second principle is autonomy, from which stems a right to determine one’s medical treatment. This is regarded as an almost inviolable right in a liberal democracy, and is also a principle that is recognized by the law. These two principles do not sit together comfortably in the context of a competent adult’s contemporaneous or advance decision to refuse life-sustaining medical treatment. Nevertheless, the legal position is clear. While the principle of sanctity of life is an important one that prevails in many circumstances, it is trumped by the principle of autonomy when the two conflict. At common law, a competent patient cannot be forced to receive unwanted treatment in order to sustain life, and a decision to refuse such treatment that is made in advance must be complied with. To a large extent, this also represents the statutory position in those jurisdictions

1 These principles and the relevant legal authority are considered in section II.
2 Note that the right to determine one’s own medical treatment is not absolute. For example, individuals may be detained and treated against their will pursuant to mental health legislation that exists in most jurisdictions.
3 See, for example, Re T (Adult: Refusal of Treatment) [1993] Fam 95 at 112; Airedale NHS Trust v Bland [1993] AC 789 at 864; Re AK (Medical Treatment: Consent) [2001] 1 FLR 129 at 134; HE v A Hospital NHS Trust [2003] 2 FLR 408 at 416; W Healthcare NHS Trust v H [2005] 1 WLR 834 at 838.
that have engaged in statutory reform. Legislation recognizes the right of a competent adult to complete an advance directive that refutes life-sustaining medical treatment.\textsuperscript{4}

It is not only the common law and legislation that recognizes a competent adult’s right to refuse treatment. There exists an enormous body of literature from the disciplines of philosophy, medical ethics and law which supports the notion of autonomy underpinning our legal framework more broadly, and specifically in the context of refusing treatment.\textsuperscript{5}

The failure to recognize autonomy would have significant implications for us as a liberal democracy. In the context of decisions to refuse treatment, the supremacy of bodily integrity itself would be at risk. An equally dangerous situation would arise if the courts, while overtly purporting to support the principle of autonomy, made decisions which undermined the spirit of the principle by actively seeking justification for not following a refusal of treatment contained in an advance directive.

Yet, it is this latter hypothesis that has troubled commentators over recent years. The approach taken by the judiciary in end-of-life cases generally, and in decisions involving advance directives that refuse life-sustaining medical treatment in particular, has been the subject of rigorous scrutiny and criticism. Commentators have argued that unjustifiable decisions have been reached because judges apply legal principles from a particular bias. This bias can stem from a judge’s particular perception of the meaning of autonomy, or from a personal

\textsuperscript{4} Statutory reform is considered in section III.
bias in favour of life, or from a bias that some lives are worth preserving regardless of expressed wishes.6

The thesis of this paper is consistent with these criticisms, namely that many judges find an advance refusal to be invalid or not applicable to a medical situation because of a moral or emotional reluctance to reach a decision that will result in the death of a vulnerable individual. This paper adds to the debate in the following ways. First, it reviews and undertakes a critical evaluation of all of the publicly available common law cases on advance directives in England and Australia.7 It deconstructs the various judgments to distil precisely the techniques and tools that are utilized by the judges in arriving at their decisions—for the most part, not to follow the advance directive. This analysis isolates a range of legal and practical factors that contribute to this outcome, and provides evidence, from the language used in the judgments themselves, of the reluctance of the judiciary to recognize such advance directives. As part of this analysis, the paper also examines a recent decision of a superior court in Australia, Hunter and New England Area Health Service v A,8 which signifies a much greater preparedness to respect individual autonomy. In upholding the individual’s advance refusal, McDougall J takes an approach which is distinctly at odds with that taken in previous English and Australian decisions. Secondly, the paper considers the legislation that operates in the United Kingdom and in Australia, and the extent to which an individual may refuse life-sustaining medical treatment in advance. The paper also considers the effect that statutory reform has had on the common law, and the extent to which the legislature has addressed the problematic issues that will be identified as arising from the common law.

Until Hunter’s case, which may herald a more enlightened judicial approach, there has not been a case in which a court has upheld an advance directive where, at the time of hearing, the adult had lost capacity. The conclusion reached is that, despite mouthing the words of autonomy and self-determination, when called upon to make decisions about advance refusals, the courts have generally been reluctant to hold that the directives should govern treatment. This reluctance is undesirable, not only for the adult whose previously expressed directive has been ignored, but for all of those in our society who wish to


7 England and Australia were chosen because there have been a reasonable number of decisions involving advance directives, as well as legislative reform in the area.

plan for medical treatment or non-treatment at the end of life. Such an approach undermines personal autonomy, a principle that underpins our liberal democracy and judicial doctrine.

II. The Common Law (as Enunciated by the Judiciary)

The common law in England, and more recently Australia, has been clearly articulated. A competent adult can refuse medical treatment even if that treatment is necessary to keep him or her alive.9 Further, a competent adult can complete a directive about the treatment he or she does not wish to receive in the future should that person later lose capacity to decide treatment.10 A medical professional who does not comply with a patient’s decision to refuse treatment may be liable to both civil and criminal sanctions.11

It necessarily follows from the above statement of legal principle that, in cases of advance refusals of life-sustaining medical treatment, the principle of autonomy prevails over that of sanctity of life. This

9 In England, see Re B (Adult: Refusal of Medical Treatment) [2002] 2 All ER 449; HE v A Hospital NHS Trust [2003] 2 FLR 408 at 414 where Munby J agrees with the assessment of Professor A. Grubb in ‘Competent adult patient: right to refuse life-sustaining treatment’ (2002) 10 Medical Law Review 201 at 203 that ‘English law could not be clearer’ on this point. In Australia, see Brightwater Care Group (Inc) v Rossiter [2009] WASC 229 at [26].

10 In England, see Re T (Adult: Refusal of Treatment) [1993] Fam 95 at 103; Airedale NHS Trust v Bland [1993] AC 789 at 864; Re C [1994] 1 All ER 819 at 824; Re AK (Medical Treatment: Consent) [2001] 1 FLR 129 at 134; HE v A Hospital NHS Trust [2003] 2 FLR 408 at 415; W Healthcare NHS Trust v H [2005] 1 WLR 834 at 836. In Australia, see Hunter and New England Area Health Service v A [2009] NSWSC 761 at [40(6)]. This was the first decision of a superior court in Australia about the validity of an advance directive at common law. However, even before this decision, this was generally accepted as representing the Australian law: see, for example, Queensland Law Reform Commission, Assisted and Substituted Decisions: Decision-making by and for people with a decision-making disability, Report No 49 (1996) Volume 1, 357; second reading speech introducing amendments to the Guardianship and Administration Act 1990 (WA) to provide for statutory advance health directives where it was assumed that common law advance directives were binding, 6 December 2006; although not expressly addressing the point, the Victorian Court of Appeal in Qumsieh v Guardianship and Administration Board & Anor [1998] VSCA 45 seemed to accept that a common law advance directive would be binding in that jurisdiction. See also I. Kerridge, M. Lowe and C. Stewart, Ethics and Law for the Health Professions, 3rd edn (The Federation Press: Sydney, 2009), 253; C. Stewart, ‘Advance Directives: Disputes and Dilemmas’ in I. Freckelton and K. Petersen (eds), Disputes and Dilemmas in Health Law (The Federation Press: Sydney, 2006) 38; J. McIlwraith and B.I. Madden, Health Care and the Law, 4th edn (Thomson Lawbook: Sydney, 2006) 132; J. Devereux, Australian Medical Law, 3rd edn (Cavendish: London, 2007) 905; L. Skene, Law and Medical Practice, 3rd edn (Lexis Nexis Butterworths: Sydney, 2008) [5.8].

position is reflected in and confirmed by the language used in end-of-life decisions. The supremacy afforded to the principle of autonomy in this context is perhaps most clearly articulated by Lord Goff in the landmark decision of Airedale NHS Trust v Bland:

First, it is established that the principle of self-determination requires that respect must be given to the wishes of the patient, so that 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 interests to do so . . . To this extent, the principle of the sanctity of human life must yield to the principle of self-determination . . . and, for present purposes perhaps more important, the doctor’s duty to act in the best interests of his patient must likewise be qualified. . . . Moreover the same principle applies where the patient’s refusal to give his consent has been expressed at an earlier date, before he became unconscious or otherwise incapable of communicating it . . . .

As part of the law’s attempt to balance the principles of sanctity of life and autonomy, effect will only be given to an advance directive that is valid and applicable to the circumstances that have arisen. If the directive is not valid, or valid but not applicable to the situation that later arises, the appropriate treatment must be determined in another way. Where there is doubt about validity or applicability, the advance refusal will not be effective. In other words, any doubt is resolved in favour of the preservation of life.

For the advance directive to be valid, the adult must have had capacity at the time the advance directive was made, and must have been able to communicate the decision about treatment. At common law, the meaning of ‘capacity’ is relatively settled and depends on the

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12 [1993] AC 789 at 864. Note that this statement was made in dicta only, as the patient in that case was a young man who was unconscious and had not previously expressed his wishes about future treatment. These comments of Lord Goff were referred to (and implicitly endorsed) in Re AK (Medical Treatment: Consent) [2001] 1 FLR 129 at 133–4; Re B (Adult: Refusal of Medical Treatment) [2002] 2 All ER 449 at 456; HE v A Hospital NHS Trust [2003] EWHC 1017 (Fam), 416.

13 See, for example, Re T (Adult: Refusal of Treatment) [1993] Fam 95 at 112; HE v A Hospital NHS Trust [2003] 2 FLR 408 at 421. For commentary on the appropriateness of using ‘bias in favour of life’ in determining the validity or applicability of an advance directive, see Michalowski, above n. 5.

14 R (Burke) v General Medical Council [2005] QB 424 at 440 (although note that, in overturning the decision, the Court of Appeal suggested caution in relying on aspects of Munby J’s judgment in future cases: R (Burke) v General Medical Council [2006] QB 273). Kennedy and Grubb suggest that there is a further requirement for validity that the adult have sufficient information on which to found a decision to refuse treatment: I. Kennedy and A. Grubb, Medical Law, 3rd edn (Butterworths: London, 2000) 2037–8. This view has also received some judicial support. Compare views expressed in L. Willmott, B. White and M. Howard, ‘Refusing Advance Refusals: Advance Directives and Life-Sustaining
ability of an adult to function rationally. Any undue influence or other vitiating factor that was exerted on the adult at the time of signing may also affect the validity of the advance directive. There are no formality requirements for the advance directive to be valid, and it can be revoked by the adult at any time.

Even if an advance directive is valid, before it will govern treatment it must also be applicable to the adult’s circumstances. To be applicable, the issue is whether the adult intended the directive to govern the medical situation that later arose. This will require a consideration of the medical condition that later confronts the adult and the directive given previously, but also of whether the adult subsequently evinced an intention no longer to be bound by the directive.

III. Statutory Reform

The law governing advance directives has undergone significant statutory reform in both the United Kingdom and Australia. While legislative reform is relatively recent in the United Kingdom, statutory reform commenced in Australia in the early 1980s and legislation has now been enacted in six of Australia’s eight jurisdictions.

The Mental Capacity Act 2005 (UK) was a long time in the making. The Law Commission examined the broader body of regulation concerning decision-making by and on behalf of individuals who lacked the capacity to make their own decisions. The Commission published a discussion paper and four consultation papers on a range of issues, followed by a final report in 1995 entitled ‘Mental Incapacity’.

Medical Treatment’ (2006) 30 Melbourne University Law Review 211 at 220–1. The proposition that the validity of an advance directive will depend on whether the directive is based on sufficient information is explored further in section V.i below.
15 See, for example, Re C (Adult: Refusal of Medical Treatment) [1994] 1 All ER 819; Re MB (Medical Treatment) [1997] 2 FLR 426; Re B (Adult: Refusal of Medical Treatment) [2002] 2 All ER 449; R (Burke) v General Medical Council [2005] QB 424.
16 For a consideration of when influence will be regarded as ‘undue’ and therefore vitiate validity, see comments of Staughton LJ in Re T [1992] 4 All ER 649 at 669.
17 HE v A Hospital NHS Trust [2003] 2 FLR 408 at 417.
18 Ibid. at 418.
19 For a detailed consideration of circumstances in which a valid advance directive is likely to be held not applicable at common law, see Willmott, White and Howard, above n. 14.
Although the United Kingdom legislation that was ultimately enacted was largely based on the recommendations of the Law Commission, there was extensive review of, and consultation on, those recommendations carried out by the government. As part of this review, the Lord Chancellor’s Department produced a Green Paper in 1997 entitled ‘Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults’ 23 and a White Paper in 1999 entitled ‘Making Decisions: The Government’s Proposals for Making Decisions on Behalf of Mentally Incapacitated Adults’. 24

Recommendations regarding advance directives about medical treatment had an interesting evolution. The final report of the Law Commission recommended that advance decisions refusing medical treatment should be enforceable and that this right should be statutorily enshrined. 25 Despite this recommendation, and despite seeking the views of the public about the enactment of legislation in its Green Paper, the government expressed the view in its White Paper that advance directives should continue to be governed by the common law only. 26 Notwithstanding the government’s position as expressed in the White Paper, the Mental Capacity Act 2005 (UK) ultimately made provision for advance directives in sections 24–6.

Legislation has evolved in the various Australian jurisdictions on an ad hoc basis, sometimes, but not always, following either a law reform commission or governmental review. Reform commenced in South Australia with the enactment of legislation in 1983. 27 This statute was subsequently repealed and replaced by the Consent to Medical Treatment and Palliative Care Act 1995 (SA). 28 The Northern Territory then enacted the Natural Death Act 1988, which was largely modelled on the earlier South Australian legislation. Victoria was next to pass legislation, the Medical Treatment Act 1988, following a review of the law by the Social Development Committee which was established by the Victorian government to inquire into a number of issues related to

27 Natural Death Act 1983 (SA).
treatment of dying patients. The Australian Capital Territory government enacted legislation in 1994 which was replaced by the Medical Treatment (Health Directions) Act 2006 (ACT). Queensland enacted the Powers of Attorney Act 1998 following a comprehensive review of the law on substitute decision-making by the Queensland Law Reform Commission. Western Australia was the most recent jurisdiction to enact legislation governing advance directives. The Acts Amendment (Consent to Medical Treatment) Act 2006 was enacted to amend the Western Australian guardianship legislation by inserting a part on advance directives. Similar to the reform process in the United Kingdom, the legislation followed a review by the Western Australian Law Reform Commission and subsequent reviews and consultation by the Western Australian Government.

These seven statutes (one in the United Kingdom and six in Australia) differ significantly in many respects, including whether directions can be made about receiving and refusing treatment, or about refusing treatment only, or about refusing life-sustaining treatment only. However, they all share one important feature: a competent person is entitled, at least in some circumstances, to make an advance directive that refuses life-sustaining medical treatment. Further, it is generally the case that an advance directive that complies with the statutory requirements must be followed by medical professionals who are treating the now incompetent person. All of the statutes therefore, at least at some level, recognize and promote the principle of autonomy.

While it is beyond the scope of this paper to comprehensively review the legislation, some of the major features of the statutory regimes should be mentioned. There are many similarities in how the statutes regulate advance directives refusing life-sustaining medical treatment, including the following:

29 The final report of the Committee, ‘Inquiring into Options for Dying with Dignity’ was delivered in April 1987.
30 Medical Treatment Act 1994 (ACT).
32 Guardianship and Administration Act 1990 Part 9B. Note that, at the time of writing, Part 9B had not yet commenced operation.
Most statutes contain a requirement that the advance directive be in writing. Many statutes require the directive to be in a prescribed form, and all of the statutes that require it to be in writing also have witnessing requirements.

All of the statutes provide, either expressly or by necessary implication, that an advance directive can only operate once the person has lost competence to make decisions.

All of the statutes provide, again either expressly or by necessary implication, that an advance directive will not operate if the person has changed his or her mind about the directive, or that circumstances have changed so that the person would no longer have intended the directive to govern treatment.

There are also some significant differences in the legislation, the major ones being:

- Some statutes provide that a directive refusing life-sustaining treatment can only operate if the person is sufficiently sick, or if the disease has reached a certain stage.

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36 Mental Capacity Act 2005 (UK), s. 25(6)(a); Consent to Medical Treatment and Palliative Care Act 1995 (SA), s. 7(2); Guardianship and Administration Act 1990 (WA), s. 110Q(1); Medical Treatment Act 1988 (Vic), s. 5(2); Natural Death Act 1989 (NT), s. 4(1); Powers of Attorney Act 1998 (Qld), s. 44(2). Compare the Australian Capital Territory where the directive may be oral or in writing: Medical Treatment (Health Directions) Act 2006 (ACT), s. 7(2).

37 Mental Capacity Act 2005 (UK), s. 25(6)(a); Consent to Medical Treatment and Palliative Care Act 1995 (SA), s 7(2); Guardianship and Administration Act 1990 (WA), s 110Q(1); Medical Treatment Act 1988 (Vic), s 5(2); Natural Death Act 1989 (NT), s 4(1). In the Australian Capital Territory, if the directive is in writing, it must be in the prescribed form: Medical Treatment (Health Directions) Act 2006 (ACT), ss 7(2) and 8. Compare Queensland where compliance with the prescribed form is optional: Powers of Attorney Act 1998 (Qld), s. 44(2).

38 Mental Capacity Act 2005 (UK), s. 25(6)(c) and (d); Consent to Medical Treatment and Palliative Care Act 1995 (SA), s. 7(2); Guardianship and Administration Act 1990 (WA), s. 110Q(1); Medical Treatment Act 1988 (Vic), s. 5(1); Medical Treatment (Health Directions) Act 2006 (ACT), s. 9; Natural Death Act 1989 (NT), s. 4(2); Powers of Attorney Act 1998 (Qld), s. 44(3).

39 Mental Capacity Act 2005 (UK), ss 24(1)(b) and 25(3); Consent to Medical Treatment and Palliative Care Act 1995 (SA), s. 7(1)(b); Guardianship and Administration Act 1990 (WA), s. 110S(1)(a); Guardianship and Administration Act 2000 (Qld), s. 66.

40 Mental Capacity Act 2005 (UK), s. 25(2); Consent to Medical Treatment and Palliative Care Act 1995 (SA), s. 7(3)(b); Guardianship and Administration Act 1990 (WA), s. 110S(3) and (6); Medical Treatment Act 1988 (Vic), s. 7(1) and (3); Medical Treatment (Health Directions) Act 2006 (ACT), ss 10(1) and 12; Natural Death Act 1989 (NT), s. 4(3); Powers of Attorney Act 1998 (Qld), s. 103.

41 In South Australia, a person must be in the terminal phase of a terminal illness before the advance directive will operate: Consent to Medical Treatment and Palliative Care Act 1995 (SA), s. 7(1)(a). In the Northern Territory, a person must be suffering from a terminal illness: Natural Death Act 1989 (NT), s. 4(1). In Queensland, the person must fall within one of the following categories before the advance directive refusing treatment can operate: the person has a terminal illness or condition that is incurable or irreversible and as a result of which, in the opinion of a doctor treating the person and another doctor, the person may reasonably be expected to die within one year; or the person is in a persistent vegetative state; or the person is permanently unconscious; or the person has an
One statute allows only a person who is suffering from a particular condition to make a directive refusing treatment. The same jurisdiction also makes the provision of information about the person’s condition a prerequisite to the validity of the directive.

Another important area of differentiation is the role played by the common law, following statutory enactment. The legislation in Western Australia and Queensland expressly preserves the common law. In those jurisdictions, it should therefore be the case that the common law on advance directives would continue to operate alongside the statutory regime. In Victoria, the Australian Capital Territory and the Northern Territory, while not expressly preserving the common law, the statute provides that other rights to refuse treatment are not affected by the legislation. In these jurisdictions too, the common law would generally continue to operate alongside the statutory regimes. In the United Kingdom and South Australia, the legislation is silent on the continued operation of the common law. The legislation in South Australia is narrow in focus, dealing only with refusal of medical treatment when someone is in the terminal phase of a terminal illness or in a persistent vegetative state. As such, it does not purport to cover the range of situations in which a person could give an advance directive at common law. It is therefore likely that the common law would continue to operate.

The position in the United Kingdom is different. Sections 24–6 of the Mental Capacity Act 2005, unlike the provisions of the South Australian statute, are comprehensive in coverage as they purport to regulate all kinds of advance refusals of treatment. While the legislation does not expressly overtake the common law, it is clear that an advance refusal of life-sustaining medical treatment can only operate

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42 Medical Treatment Act 1988 (Vic), s. 5(1)(a).
43 Medical Treatment Act 1988 (Vic), s. 5(1)(c).
44 Guardianship and Administration Act 1990 (WA), s. 110ZB and Powers of Attorney Act 1998 (Qld), s. 39 respectively.
45 Note, however, that the provision may not have been effective in Queensland to preserve the common law. Despite s. 39 of the Powers of Attorney Act 1998 (Qld) which purports to preserve the common law, it is likely that, due to a drafting error when enacting Queensland’s guardianship regime (comprised of Powers of Attorney Act 1998 (Qld) and the Guardianship and Administration Act 2000 (Qld)), the common law regime no longer applies in Queensland: see B. White and L. Willmott, ‘Will you do as I ask? Compliance with instructions about health care in Queensland’ (2004) 4 Queensland University of Technology Law and Justice Journal 77.
46 Medical Treatment Act 1988 (Vic), s. 4; Medical Treatment (Health Directions) Act 2006 (ACT), s. 6(1); Natural Death Act 1989 (NT), s. 5(1).
47 This view is shared by legal commentators. See, for example, C. Stewart, ‘The Australian experience of advance directives and possible future directions’ (2005) 24 Australasian Journal on Ageing 525.
if it complies with the formality requirements. This leaves no further room for the operation of informal advance directives. This position is also evident from the transitional provisions. In relation to decisions that refuse life-sustaining treatment, the transitional provisions indicate that common law advance directives entered into before the commencement of the legislation on 1 October 2007 will only operate if they satisfy the provisions of the transitional instrument. It follows that common law directives that do not comply will not be binding. The implication is that the statutory scheme has effectively overtaken the common law in relation to advance directives that refuse life-sustaining medical treatment.

Despite the legislative reform described above, it is submitted that the common law will continue to play a significant role in relation to advance refusals of life-sustaining treatment in all jurisdictions. In those jurisdictions that have both statutory and common law regimes, an individual may still make a binding common law directive and there is no obligation for that directive to comply with legislative requirements. Further, an unsuccessful attempt to complete a statutory advance directive may still be effective as a common law directive.

It is likely that the common law and approaches taken by the judiciary in developing common law principles will also continue to play a role in jurisdictions, such as the United Kingdom, where the common law has become embedded in statute. First, the common law has developed a body of jurisprudence which is likely to be influential when interpreting the statute. Further, the interpretation of some words and phrases that are used in the legislation may be informed by relevant case law and commentary on the common law position. Secondly, the approaches taken by judges in the common law cases will be relevant. Should doubt arise about the existence, validity or applicability of a statutory advance directive, the matter will be determined by the newly established Court of Protection. Members of the court, which is headed by a former President of the Family Division of the High Court, may well be influenced by, or indeed agree with, the attitudes of and approaches taken previously by the High Court (and the Court of Appeal) when considering the validity and applicability of advance directives at common law. As with most pieces of complex legislation, there will undoubtedly be many provisions in the Mental Capacity Act 2005 that will require judicial interpretation. Some areas of ambiguity in relation to advance refusals of medical treatment have

50 Mental Capacity Act 2005 (UK), s. 26(4).
already been identified.\textsuperscript{51} Judicial attitudes to date suggest an unwillingness or reluctance to uphold common law directives that refuse treatment. Under the statutory regime, the willingness or otherwise of a judge to allow the autonomous choice of an individual to prevail will continue to be critical.

Statutory provisions from the United Kingdom and Australian statutes will be considered below where they assist in informing a consideration of the common law.

\section*{IV. The Common Law (as Applied by the Judiciary)—An Overview}

There have been only a handful of cases in which courts have been called upon to decide whether advance directives that refuse life-sustaining treatment should be followed by medical professionals. In England and Australia, there have been eight such decisions over the past two decades, with six being decided since 2000:

- \textit{Re C (Adult: Refusal of Medical Treatment)}\textsuperscript{52}—advance directive followed (High Court, England)
- \textit{Re AK (Medical Treatment: Consent)}\textsuperscript{53}—advance directive followed (High Court, England)
- \textit{HE v A Hospital NHS Trust}\textsuperscript{54}—advance directive not followed (High Court, England)
- \textit{W Healthcare NHS Trust v H}\textsuperscript{55}—advance directive not followed (Court of Appeal, England)
- \textit{NHS Trust v T (Adult Patient: Refusal of Medical Treatment)}\textsuperscript{56}—advance directive not followed (High Court, England)
- \textit{Qumsieh’s case}\textsuperscript{57}—advance directive not followed (Guardianship and Administration Board, Victoria, Australia)\textsuperscript{58}
- \textit{State of Qld v Astill}\textsuperscript{59}—advance directive not followed (Supreme Court of Queensland, Australia)

\textsuperscript{51} See, for example, Maclean, above n. 6 who gives an example the scope for interpretation. Maclean refers to section 24, which allows a person to refuse ‘specified treatment’. A narrow reading of that provision may mean that the term does not extend to the refusal of life-sustaining medical treatment generally. This ambiguity gives a court the ability to hold that a general advance refusal falls outside of the statutory scheme.

\textsuperscript{52} [1994] 1 All ER 819.
\textsuperscript{53} [2001] 1 FLR 129.
\textsuperscript{54} [2003] 2 FLR 408.
\textsuperscript{55} [2005] 1 WLR 834.
\textsuperscript{56} [2005] 1 All ER 387.
\textsuperscript{57} Unreported decision, Guardianship and Administration Board, L Pilgrim, 24 February 1998.
\textsuperscript{58} This matter went on appeal, although the decision of the Board was not reviewed: see further Appendix.
\textsuperscript{59} Unreported decision, Supreme Court of Queensland, Muir J, 18 January 2006.
It is interesting to speculate as to why so few cases have resulted in litigation, particularly given the likelihood that common law advance directives would not be an uncommon feature of medical practice. It is perhaps the case that, generally speaking, advance directives are complied with by medical professionals so there is no dispute that requires adjudication. It is also possible that many individuals who are concerned about non-compliance with an advance directive are unwilling for the dispute to be resolved through an adversarial judicial process. The narrow timeframe in which many such decisions must be made may also be a factor in the small number of cases that have been litigated.

An interesting feature of the decided cases is that they all involve an advance directive being given with a particular medical context in mind. In four of the cases, the individuals were either Jehovah’s Witnesses or had adopted some of the beliefs of that faith. The advance directives in these cases had been given for the specific reason of refusing blood products or other surgical intervention. Two other cases involved a 19-year-old man and a 59-year-old woman who were suffering from motor neurone disease and multiple sclerosis respectively. Their advance directives were given with their diseases in mind. In the remaining two cases, the individuals were a 68-year-old man and a 37-year-old woman who suffered from mental illnesses, paranoid schizophrenia and a borderline personality disorder respectively. The man needed surgery because of a medical condition and the woman had a long history of self-harm through blood-letting, and no longer wanted to receive blood transfusions to keep her alive following such incidents. In other words, in none of these cases had the adult made an advance directive in the abstract, without a particular medical situation being contemplated.

Given this context, namely the relative certainty of the medical situation or the desired outcome, it might be predicted that the advance directives would be followed, and the treatment not provided to the individual. However, this has not been the trend in the eight decisions, where the individual’s advance directive was followed in only three cases.\(^{61}\)

These eight cases are examined in the next section. While some of the decisions handed down are supportable, it is submitted that there are also some troubling aspects of the decision-making process that have been employed by the relevant courts. The following analysis casts doubt on whether the principle of self-determination in reality

\(^{60}\) [2009] NSWSC 761.

\(^{61}\) See Appendix for a summary of each case and the court’s determination.
prevails over the principle of sanctity of life. The decided cases suggest that the courts are loath to respect an advance directive that refuses life-sustaining treatment where following the directive will result in the death of an individual, even where, on an objective assessment, the directive is valid and applicable to the circumstances. The courts seem to be overly influenced by or concerned about the ‘bias in favour of life’, which results in decisions being made that are not supportable on an objective assessment of the facts.62 The undue ‘bias in favour of life’ permeates many aspects of the courts’ deliberations and judgments even where there is no evidence of doubt. The analysis that follows provides evidence of this bias in favour of life which has, in some cases, resulted in decisions that are difficult to justify. As explored in the next section, there are three legally significant factors that have contributed to an outcome (of not following an advance directive) that is not entirely defensible:

- An unprincipled evolution of common law principles;
- Inappropriate adjudication by judicial or quasi-judicial bodies; and
- Strained interpretation of facts by judicial or quasi-judicial bodies.

In addition, there is a fourth factor which, although not directly contributing to a particular outcome, is evidence of, and provides some insight into, the reluctance of some judges to uphold an advance directive that refuses life-sustaining medical treatment.

V. Unprincipled Evolution of Common Law Principles

The only requirement for an advance directive to be valid is that the adult possessed the requisite capacity at the time of completion, could communicate the treatment decision, and there were no vitiating factors such as undue influence or duress present at the time of its completion.63 Nevertheless, some of the cases signal an unprincipled evolution of common law principles which effectively place more legal obstacles in the way of medical professionals relying on an individual’s previously expressed wish to refuse treatment. These developments are difficult to justify on the basis of established legal principle.

i. Requirement that the Advance Directive be Based on Sufficient Information

In addition to the requirements of capacity, the ability to communicate and the absence of vitiating factors, statements in some of the cases

62 Compare Maclean, above n. 6, where he argues that the judiciary only selectively uphold advance directives, choosing to uphold only those that they regard as being ‘reasonable’. See also Michalowski, above n. 5.
63 See section II and nn. 14 and 16 above.
suggest that an advance directive will only be valid if it is based on sufficient knowledge or information. The suggestion is that the adult must be informed about treatment options before giving the directive, or at least has made the advance directive with knowledge of his or her illness and its likely progress. Two of the common law cases concerning advance directives support this view.

In Re AK (Medical Treatment: Consent), AK, who was suffering from motor neurone disease, gave a direction that he wanted artificial ventilation stopped two weeks after he could no longer communicate. While finding that the directive was valid, Hughes J made a number of observations about the care that a court must take in coming to such a conclusion:

Care must be taken to investigate with what knowledge the expression of wishes was made. All the circumstances in which the expression of wishes was given will of course have to be investigated. In the present case the expressions of AK’s decision are recent and are made not on any hypothetical basis but in the fullest possible knowledge of impending reality. I am satisfied that they genuinely represent his considered wishes and should be treated as such [emphasis added].

The implication is that an advance directive must be made with at least some knowledge, though the extent of knowledge is not elaborated upon by his Honour.

The law, as articulated by Hughes J, was specifically endorsed by Munby J in HE v A Hospital NHS Trust in coming to his decision that a formal advance directive previously completed by a 24-year-old woman could no longer be regarded as operative.

A different approach was taken recently by the New South Wales Supreme Court in Hunter and New England Area Health Service v A.

64 This view is also advanced by some commentators, purportedly relying on comments of Donaldson MR in Re T (Adult: Refusal of Treatment) [1993] Fam 95 at 115: see Kennedy and Grubb, above n. 14 at 2037 and Michalowski, above n. 5 at 958. Although Donaldson MR referred to the need to advise a patient in broad terms of the nature and effect of the procedure before obtaining consent or refusal, he rejected the notion that ‘informed refusal’ had become part of English common law, and stopped short of suggesting that a level of information was required for an advance refusal to be valid. As such, this case is not considered further in this section of the paper.

65 [2001] FLR 129.

66 Ibid. 134.

67 [2003] 2 FLR 408 at [32].

68 Note that similar suggestions were made by the Michigan Court of Appeals in the United States decision of Werth v Taylor 475 NW 2d 426 (1991). Despite the patient, a Jehovah's Witness, completing a number of 'Refusal to Permit Blood Transfusion' forms, the medical professional gave the patient a blood transfusion. In finding that the prior refusal did not bind the doctor, the court commented that 'her refusals were . . . not contemporaneous or informed': 475 NW 2d 426 (1991), [150]. The court continued that '[w]ithout contemporaneous refusal of treatment by a fully informed, competent adult patient, no action lies for battery' (emphasis added): 475 NW 2d 426 (1991), [150].

a case involving a Jehovah’s Witness who had completed a document refusing dialysis. While not citing any authority in support, McDougall J referred to the proposition that failure to provide adequate information could operate to vitiate a refusal of treatment.70 His Honour, however, rejected this notion, and commented as follows:

I do not accept the proposition that, in general, a competent adult’s clearly expressed advance refusal of specified medical procedures or treatment should be held to be ineffective simply because, at the time of statement of the refusal, the person was not given adequate information as to the benefits of the procedure or treatment (should the circumstances making its administration desirable arise) and the dangers consequent upon refusal. As I have said, a valid refusal may be based upon religious, social or moral grounds, or indeed on no apparent rational grounds; and is entitled to respect . . . regardless.71

It is submitted that this latter approach is more consistent with both authority and the reality of life. It is contrary to established common law principles to impose an additional requirement, over and above capacity, the ability to communicate and the absence of vitiating factors, that an adult must be informed or have knowledge about the progress of his or her illness or about treatment options for his or her advance directive to be valid. The imposition of such a requirement is inconsistent with the law regarding the ability of a competent adult to contemporaneously refuse a life-sustaining measure. It is now settled law that:

Prima facie every adult has the right and capacity to decide whether or not he will accept medical treatment, even if a refusal may risk permanent injury to his health or even lead to premature death. Furthermore, it matters not whether the reasons for the refusal were rational or irrational, unknown or even non-existent.72

Consistent judicial pronouncements have since been made on many occasions.73 If the law accepts that a competent adult may refuse life-sustaining medical treatment even if his or her reasons for doing so are ‘irrational, unknown or even non-existent’, it must follow that the decision can be made in the absence of knowledge or information that would inform the decision. The suggestion that the reasons for the decision may be ‘non-existent’ implies that the decision could be

70 Ibid. [27].
71 Ibid. [28].
72 Re T (Adult: Refusal of Treatment) [1993] Fam 115 at 664.
73 See, for example, Airedale NHS Trust v Bland [1993] AC 789 at 864; Re MB (Medical Treatment) [1997] 2 FLR 426 at 432; Re B (Adult: Refusal of Medical Treatment) [2002] 2 All ER 449 at 455–6; HE v A Hospital NHS Trust [2003] 2 FLR 408 at 414.
made without good cause, or without all or any of the relevant information.\^74

That a competent person may refuse treatment without receiving all relevant information also reflects the reality of life. A person may have a life-threatening disease or illness, but may choose not to seek medical advice or, if sought, to refuse medical treatment that is offered. The state does not and cannot intervene in such circumstances to compel medical treatment. Provided that the adult has capacity, the decision not to seek medical treatment, or to refuse medical treatment that is offered, is clearly a valid decision. This is the case whether or not the decision not to seek medical advice, or to refuse treatment, is based on full or any knowledge about the illness or treatment options.

If this is correct, as it must be, then the same must be the case for an advance refusal. There is no principled reason for suggesting that an adult must have a greater knowledge of relevant facts about, for example, the illness or treatment options, just because he or she seeks to refuse treatment in advance of the medical situation arising. If a court disregards an individual’s advance directive because it is based on insufficient knowledge or information, the court will effectively be compelling the individual to receive medical treatment, an outcome that is demonstrably unacceptable when considered in the context of a contemporaneous refusal. It should be equally unacceptable for an advance refusal.\^75

It is certainly appropriate to investigate the circumstances in which the expression of wishes was given. For example, a court must be satisfied that the directive was given in the context of deciding his or her future treatment, and was not an abstract thought about medical treatment in general. However, for the reasons just explained, it cannot be the case that the adult must possess a greater degree of knowledge when completing the advance directive for it to be valid. Such an obligation is illogical, inconsistent with authority and represents an unjustifiable extension of (or departure from) common law principles.

\^74 Compare the contrary suggestion by Martin CJ in the recent Western Australian decision of Brightwater Care Group (Inc) v Rossiter [2009] WASC 229, a case involving a request by a competent adult, a quadriplegic, to have his artificial hydration and nutrition tube withdrawn. Martin CJ suggested that the common law right to determine and direct the extent of treatment is dependent on whether he has been ‘provided with full information with respect to the consequences of any decision he might make’: [2009] WASC 229, [49].

\^75 For support for the proposition that an advance directive will be valid in the absence of knowledge or information about the individual’s condition or treatment options, see Willmott, White and Howard, above n. 14 at 220–2. This view is also consistent with the views expressed by J. Munby QC, as he then was, in ‘Rhetoric and reality: The limitations of patient self-determination in contemporary English law’ (1998) 14 Journal of Contemporary Health Law and Policy 315 at 316–17.
(a) Effect of Statutory Reform
It is interesting to observe that a requirement to receive information about the condition and treatment options has not, as a general proposition, been imposed by legislation as a prerequisite for an advance directive that refuses life-sustaining medical treatment. In the United Kingdom, while a person is encouraged to discuss an advance directive with his or her medical professional, failure to do so does not invalidate the advance directive. The position is different in Victoria where a medical professional must certify that the person has been informed about his or her condition to an extent which is reasonably sufficient to enable him or her to make a decision about refusing treatment.

ii. Issues of Proof
As outlined earlier, a competent adult can refuse life-sustaining medical treatment. If a person lacks capacity or his or her decision is overborne by the influence of another, the refusal of treatment will not be legally effective. However, an important point is that the law presumes that a person has capacity to make decisions about their health care. This presumption applies in relation to all kinds of health care, even if the decision is to refuse medical treatment that is needed to sustain a person’s life. If a person’s capacity to refuse treatment is disputed, the burden of proving that this is the case will therefore rest with the person alleging a lack of capacity. Similarly, a person who is alleging that the decision to refuse treatment is made as a result of undue influence exercised by another party will need to prove this to be the case.

The same issues are relevant for an advance refusal. The advance directive must be valid at the time of its execution. To be a valid advance refusal, the adult must have capacity and the directive must be made free of undue influence. The same presumption as above

77 Medical Treatment Act 1988 (Vic), s. 5(1)(c). Compare the legislation enacted in Western Australia, where a person is ‘encouraged’ to obtain medical advice prior to completing an advance directive, but failure to seek or receive that advice does not make the advance directive invalid: Guardianship and Administration Act 1990 (WA), ss 110Q(1)(b) and (2) and 110QA.
78 See, for example, Re T (Adult: Refusal of Treatment) [1993] Fam 95 at 116.
79 Re T (Adult: Refusal of Treatment) [1993] Fam 95 at 112; Re C [1994] 1 All ER 819 at 823–4; Re MB (Medical Treatment) [1997] 2 FLR 426 at 436; Re B (Adult: Refusal of Medical Treatment) [2002] 2 All ER 449 at 457; HE v A Hospital NHS Trust [2003] 2 FLR 408 at 415; NHS Trust v T (Adult Patient: Refusal of Medical Treatment) [2005] 1 All ER 387 at 404–5.
80 Note, however, that the degree of capacity required to make a decision with grave consequences is higher than for other kinds of decisions: see, for example, Re T (Adult: Refusal of Treatment) [1993] Fam 95 at 113; Re MB (Medical Treatment) [1997] 2 FLR 426 at 437; Re B (Adult: Refusal of Medical Treatment) [2002] 2 All ER 449 at 458.
81 HE v A Hospital NHS Trust [2003] 2 FLR 408 at 415.
82 For the purpose of this examination, it will be assumed that the adult had the ability to communicate decisions, another prerequisite for validity.
applies in relation to capacity: the law presumes that the adult had capacity to make the advance directive and, if anyone disputes that capacity, the burden of proof will rest on the person making the allegation. The same principle would logically apply if a person is alleging that the advance directive was made as a result of undue influence. However, there are additional considerations that are relevant in determining whether a medical professional should, at some later time, rely on an advance directive. First, because of circumstances that have arisen since its completion, the medical professional may legitimately query whether the directive remains valid. Secondly, the medical professional must be satisfied that the advance directive is applicable to the medical situation that has arisen.

A concerning feature of the case law on advance directives is that, at least in England, an unprincipled approach has evolved to issues of proof. The problematic authority is the following passage from Munby J in *HE v A Hospital NHS Trust*:

> [23] Burden of proof: in my judgment, although the burden of proof on the issue of capacity is on those who seek to dispute it, the burden of proof is otherwise on those who seek to establish the existence and continuing validity and applicability of an advance directive. So if there is doubt that doubt falls to be resolved in favour of the preservation of life.

Issues of burden and standard of proof will only be relevant once a matter is before a court. If the matter involves an advance directive, the court must determine whether the advance directive was valid at the time of completion, continued to be in existence and is applicable in the medical situation that has arisen. This determination is made on the evidence before the court. The problem is Munby J’s assertion that the person who is suggesting that the advance directive should operate has the onus of proving this to be the case. This assertion is problematic at both legal and practical levels.

**(a) Legal Concerns**

First, the assertion that the person ‘seeking to establish the existence and continuing validity and applicability of an advance directive’ has the burden of proof must be open to question. A court will not uphold an advance directive unless there is evidence that it was valid at the

83 *HE v A Hospital NHS Trust* [2003] 2 FLR 408 at 415.
84 While none of the cases on advance directives have engaged with the issue of onus of proof if undue influence is alleged, it is submitted that the person alleging such influence must discharge the onus of proof. Support for this assertion can be drawn from the analogous situation where it is claimed that undue influence was exercised over a testator when executing a will. Case authority in both England and Australia provides that the onus of proving undue influence in such a case rests on the party who alleges it: *Boyse v Rossborough* (1857) 10 ER 1192 at 1211 and *Winter v Crichton* (1991) 23 NSWLR 116 at 121.
85 [2003] 2 FLR 408.
time of execution, and that it applies to the situation that has arisen. To this extent, it is appropriate to suggest that a person who claims its existence and applicability should lead evidence to that effect. However, if the court is satisfied of these factors, it is questionable whether the same person should be required to prove its continued existence. The court, at this point, should require the person claiming that the advance directive was no longer in existence to discharge the burden of proving this. While Munby J concedes that a person asserting that the advance directive is no longer operative must point to something suggesting why this may be so, at no stage does his Honour suggest that a person claiming invalidity has an onus to discharge. His Honour falls short of suggesting that, once the validity and applicability of the advance directive is established in the first instance, the onus shifts to the person disputing the continued validity and applicability of the advance directive to prove that on the balance of probabilities.

There also seems to be an inconsistency about the extent to which the validity or applicability of the directive needs to be called into question. At one stage in his judgment, Munby J suggests that there needs to be ‘some real reason to doubt’ its validity or applicability, while elsewhere he suggests that ‘if there is doubt that doubt falls to be resolved in favour of the preservation of life’. The latter phrase seems to suggest something less than a ‘real reason to doubt’ may be all that is required.

Further, Munby J’s assertion regarding the onus of proving the continued validity and applicability is not supported by the three authorities on which he purports to rely: Re T (Adult: Refusal of Treatment),86 Airedale NHS Trust v Bland87 and Re AK (Medical Treatment: Consent).88 The relevant extracts from the cases that are cited by Munby J urge caution in interpreting an advance directive, and make it clear that if there is doubt, the sanctity of life is favoured. However, there is no suggestion that a person claiming that the advance directive should govern treatment must discharge any onus of proof. To this extent, Munby J’s claim that a person has such an onus, is not based on legal precedent.

A different approach and, it is submitted, one more consistent with authority, was taken by McDougall J in Hunter and New England Area Health Service v A.89 When considering whether the advance directive was valid and applicable to the situation, his Honour made the following comments:

There is a presumption that an adult is capable of deciding whether to consent to or to refuse medical treatment. However, the presumption is rebuttable. . . . If there is genuine and reasonable doubt as to the validity of an advance care directive, or as to whether it applies in the situation

86 [1993] Fam 95.
88 [2001] FLR 129.
at hand, a hospital or medical practitioner should apply promptly to the court for its aid.\textsuperscript{90}

Two observations are relevant here. First, McDougall J does not refer to any obligation on a party to prove the \textit{continuing} validity and applicability of the advance directive. The implication is that if the advance directive was valid when executed and is applicable to the situation that has arisen, the \textit{prima facie} position is that it should be followed. This is in conflict with Munby J’s position. Secondly, McDougall J suggests that the advance directive should be challenged only if there is a ‘genuine and real doubt’ regarding its validity or applicability. This puts the test somewhat higher than that articulated by Munby J.

The second cause for legal concern arising from Munby J’s statements is that statements about the burden of proof are premised on the fact that the matter has come before the court in an adversarial context. This will not always be the case. A hospital, for example, may seek declaratory relief about whether it is bound to follow an advance directive that had been completed by an incompetent patient who now requires treatment to save his or her life.\textsuperscript{91} In such a case, there is no ‘person seeking to establish the validity and applicability of the directive’ in the sense of actively advocating that the advance directive should be followed. It is unclear how Munby J suggests the onus of proof would be discharged in such a situation.

\textbf{(b) Practical Concerns}

Munby J’s approach also raises concerns on a practical level, namely the limited number of cases in which a person will be able to discharge the onus and standard of proof that is advocated by his Honour. Imposing an onus about the ‘continuing validity’ on an individual is problematic. Take the hypothetical case of an adult who had been a practising Jehovah’s Witness all of her life. At age 30, she completes an advance directive refusing blood products in all situations. This advance directive is kept with her general practitioner. Ten years later, she is involved in a car accident and is taken to a hospital where a decision must be made about a blood transfusion that is needed to save her life. The treating team is aware of her advance directive as they have contacted her doctor. This woman is still a Jehovah’s Witness but she has not discussed her faith with her doctor since completing the advance directive. The hospital brings an application to court seeking declaratory relief. Applying the dicta of

\textsuperscript{90} Ibid. [40(7)]–[40(8)].

\textsuperscript{91} See, for example, \textit{Hunter and New England Area Health Service v A} [2009] NSWSC 761, where the Health Service was seeking declaratory relief about the validity of the advance directive completed by the adult.
Munby J, the onus of establishing the continuing validity and applicability of the advance directive could not be satisfied. First, the applicant (the hospital) is not ‘seeking to establish’ the existence, continuing validity or applicability of the advance directive in the sense of arguing for a particular position. Secondly, there is no evidence at all of its continuing validity. The only evidence is of its original validity. Does this mean that the advance directive could be ignored? Would the situation be the same if the woman in question had been in the car accident only one year, one month, or one day after completing the advance directive?

A related but separate concern is Munby J’s observation that the continuing validity and applicability of an advance directive must be established by ‘clear and convincing proof’. While stating that the test is the usual civil standard of proof on the balance of probability, Munby J notes that the evidence must be stronger and more cogent because of the gravity of the matter.92 There is a practical difficulty with requiring clear and convincing proof of the advance directive’s continuing validity and applicability. The case of HE v A Hospital NHS Trust93 itself illustrates this concern. This case involved a Muslim woman, AE, who was raised by a Jehovah’s Witness, and who had signed an advance directive refusing blood products. At the time of its execution, AE must have been emphatic about her desire not to receive blood products because the directive also contained a clause providing that the directive could only be revoked in writing. Almost two years later, when contemplating surgery, she confirmed her desire not to receive blood products, and these instructions formed part of the hospital notes. Five months after that verbal confirmation, the validity of the directive was challenged, and the court held that there was not clear and convincing evidence of the directive’s continuing validity and applicability. The medical professionals were authorized to treat AE in a way that promoted her best interests. In coming to this decision, the court relied on verbal evidence of AE’s father, a Muslim, that she changed her faith four months prior to the hearing, which was one month after she told her doctor that she did not want blood products. This evidence contradicted that of AE’s mother, a Jehovah’s Witness, who advised hospital staff on AE’s admission that AE continued to be of the Jehovah’s Witness faith.

In this case, the adult had gone to significant lengths to set out her wish to refuse blood products. A formal document was drawn up, and that document included a clause saying that the refusal is absolute and

92 Munby J has subsequently reiterated his view about the need for ‘clear and convincing proof’ in relation to an advance directive refusing life-sustaining measures: The Queen (on the application of DJ) v The Mental Health Review Tribunal [2005] EWHC 587 at [61]. Note, however, criticisms of Munby J’s approach when this case went on appeal to the Court of Appeal: R (on the application of AN) v The Mental Health Review Tribunal (Northern Region) [2006] QB 468.
93 [2003] 2 FLR 408.
not to be overridden in any circumstances by a purported consent of a relative or other person. If a formal document of the kind used in this case coupled with a later verbal confirmation that it still represented her wishes do not constitute ‘clear and convincing proof’ of its continuing validity, it is difficult to envisage a case where this standard of proof could be satisfied.

The approach taken by Munby J regarding the onus of proof is difficult to justify and not consistent with established legal principles. The practical consequences of such an approach, particularly in light of the requirement for the standard of proof to be ‘clear and convincing’, is that it is unlikely that an individual’s advance directive refusing treatment will be followed. It is submitted that the approach taken by McDougall J in Hunter and New England Area Health Service v A \(^94\) should be preferred as it is consistent with legal authority, and more likely to result in outcomes that were intended by the individual who made the advance directive.

(c) Effect of Statutory Reform

It is unlikely that legislation has affected the common law principles that have been discussed above about burden and standard of proof. In the United Kingdom and in a number of the statutes in Australia, the legislation contains a presumption that an adult has capacity for a particular decision.\(^95\) As such, evidence must be produced before that presumption can be rebutted. In the United Kingdom, the legislation specifically provides that the standard of proof is on the balance of probabilities.\(^96\)

Also relevant to issues of proof is the protection that is provided by the Mental Capacity Act 2005 (UK) to a medical professional who is confronted with an advance refusal. He or she does not incur liability for carrying out treatment unless ‘satisfied’ that an advance decision refusing treatment has been given.\(^97\) There is no requirement that the medical professional act reasonably in forming that view.\(^98\) This is in contrast to the protection afforded if treatment is withheld pursuant to an advance decision. In the latter case, a medical professional is protected only if he or she ‘reasonably believed’ that the advance

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\(^94\) [2009] NSWSC 761.

\(^95\) In the United Kingdom, see Mental Capacity Act 2005 (UK), s. 1(2). In Australia, see the legislation of Queensland and Western Australia: Guardianship and Administration Act 2000 (Qld), sch 1, s. 1; Guardianship and Administration Act 1990 (WA), s. 4(1)(b) respectively.

\(^96\) Mental Capacity Act 2005 (UK), s. 2(4).

\(^97\) Mental Capacity Act 2005 (UK), s. 26(2). Compare the Queensland legislation which excuses a medical professional from ignoring an advance directive that refuses treatment if he or she has reasonable grounds to believe that the direction is ‘contrary to good medical practice’: Powers of Attorney Act 1998 (Qld), s. 103.

\(^98\) Note that the Mental Capacity Act 2005 (UK), Code of Practice [9.58] provides that a medical professional would not be ‘satisfied’ if he or she had ‘genuine doubts’ about the advance decision.
decision was applicable. Where there is doubt, the matter can be resolved by the Court of Protection. Given the failure of the legislation to impose an objective standard that the medical professional be ‘satisfied’ about the advance decision, and given the identified reluctance of courts to uphold advance decisions that refuse treatment, it can be predicted that courts may readily be persuaded that a medical professional is not ‘satisfied’ that an advance decision applies to treatment. If this occurs, medical professionals could, in reality, receive a considerable amount of protection should they not comply with an advance decision to refuse treatment.

VI. Inappropriate Adjudication by Judicial or Quasi-judicial Bodies

From a strictly legal perspective, the most alarming feature arising from a review of the case law is the inappropriate conduct of judicial (or quasi-judicial) bodies in hearing matters relating to the refusal of treatment. Although some cases are brought in an emergency context, the lack of familiarity with or ability to apply legal principles is a recurring theme. This inappropriate adjudication manifests itself in two ways: operational irregularities or failures, and a failure to apply correct legal principles.

i. Operational Irregularities or Failures

An important case from the Australian State of Victoria concerning refusal of blood products may well have been decided differently had the determining body more appropriately discharged its duties. Qumsieh’s case involved Q, a Jehovah’s Witness, who needed a blood transfusion to sustain her life following the birth of her child. Q had previously indicated that she did not want to receive blood products due to her religious beliefs. Despite his wife’s expressed position regarding blood transfusions, Q’s husband brought an application to the Victorian Guardianship and Administration Board for the appointment of a substitute decision-maker to make a decision about medical treatment on Q’s behalf.

The hearing was attended by Q’s husband, his solicitor and the hospital’s solicitor. The board was advised that Q did not want to receive a blood transfusion and was also given the consent form in which she refused blood or blood products in the context of treatment to be carried out under anaesthetic. The board was not advised why Q refused such products, nor was it given a copy of her ‘Advance Medical Directive’ which contained a blanket refusal of blood products.

99 Mental Capacity Act 2005 (UK), s. 26(3).
100 For further consideration of this issue, see Bartlett, above n. 49 at 82–3 and Maclean, above n. 6.
Being satisfied that Q was no longer able to make medical decisions for herself, the board appointed the Public Advocate as her guardian, and her husband was ordered to be the delegated guardian of the Public Advocate. He made a decision to allow the transfusion.\textsuperscript{102} The decision of the board was flawed because it did not ensure that it had received all information relevant to its determination.\textsuperscript{103} The board should have asked the parties why Q refused a blood transfusion, and whether it had before it all relevant documentation in relation to that refusal. Not seeking such crucial evidence constituted a failure by the board at an operational or practical level. Had the board been advised that Q refused blood because of her religious beliefs, and had read her Advance Medical Directive refusing blood products, it is unlikely that it would have concluded that:

\ldots [i]t had no evidence before it that the proposed represented person did not want a guardian appointed to make health care decisions, outside her wishes expressed in the \ldots informed consent form \ldots which was limited to an examination under anaesthetic.\textsuperscript{104}

Instead, the board is likely to have dismissed the application for the appointment of a guardian on the basis that the adult, while still competent, had indicated that she did not want to receive the proposed treatment in the situation that arose.\textsuperscript{105}

\textit{ii. Failure to Apply Correct Legal Principles}

Cases in which an urgent determination must be made about whether life-sustaining treatment should be administered to a person who might otherwise die but who has indicated an objection to that treatment, are difficult. They are often brought before a court at short notice, facts might be sketchy and legal argument is unlikely to be comprehensive. Nevertheless, it is a concern when incorrect legal principles are applied, particularly where the judgments signal that the application of legal principle and exploration of the adult’s wishes

\textsuperscript{102} The board’s decision was unsuccessfully reviewed by Beach J of the Supreme Court of Victoria. A transcription was not made of his Honour’s reasons for his decision to decline the application to review. The Supreme Court of Victoria Court of Appeal dismissed an appeal against the decision of Beach J in \textit{Qumsieh v The Guardianship and Administration Board} [1998] VSCA 45. For comment on the decision of the Court of Appeal, see section VIII.i below.

\textsuperscript{103} Pursuant to the then s. 10(3) of the Guardianship and Administration Act 1986 (Vic), the board was not bound by rules or practice as to evidence but was empowered to inform itself in relation to any matter in such manner as it thought fit.

\textsuperscript{104} As cited in \textit{Qumsieh v The Guardianship and Administration Board} [1998] VSCA 45, [8].

\textsuperscript{105} For a further example of a procedural irregularity, although in the context of a contemporaneous refusal of blood products, see \textit{Fitzpatrick v K} [2008] IEHC 104 where K refused a blood transfusion following the birth of her child. The hospital brought an \textit{ex parte} application to the High Court for a direction that K receive blood. K, although conscious for most of the relevant time, was neither advised of the application, nor was legal counsel appointed on her behalf to represent her position.
are secondary to the overall desire to sanction the provision of life-sustaining treatment.

(a) Failure to Consider Whether Statements Constitute an Advance Directive
The decision of Muir J of the Queensland Supreme Court in State of Qld v Astill\textsuperscript{106} is illustrative of this concern. The hospital brought an application to the Supreme Court to administer a blood transfusion to A, a Jehovah’s Witness, contrary to the views expressed in her advance directive. A’s daughter wanted her mother to receive the transfusion, while her two sons wanted the hospital to adhere to her mother’s wishes to refuse treatment. The court ordered the transfusion to be given if a medical practitioner considered it necessary in order to save her life or to enhance her prospects of recovery. In other words, A’s expressed wishes were not followed. Of concern is how that decision was reached.

At the outset of its judgment, the court considered the advance directive completed by A. Because it did not comply with the formalities of the relevant Queensland legislation, Muir J held that it ‘had no efficacy’. The problem is that Muir J did not then consider whether the document completed by A still constituted a common law advance directive and, if it did, whether that directive would be binding on the treating team. This failure was crucial. If it were held to be a common law advance directive, that conclusion being highly probable on the facts of the case, then the court should have considered whether, under the Queensland legislation, that advance directive would be binding. If it were, that should have been the end of the matter and the court may have dismissed the hospital’s application. A’s wishes would have been respected, and the transfusions not given.\textsuperscript{107}

(b) Misguided Reliance on Precedent
In W Healthcare NHS Trust v H,\textsuperscript{108} the English Court of Appeal had to determine whether earlier statements made by KH constituted an

\textsuperscript{106} Unreported decision, Supreme Court of Queensland, Muir J, 18 January 2006.
\textsuperscript{107} A similar misunderstanding of the true nature of an advance directive has occurred in other jurisdictions. See, for example, Werth v Taylor 475 NW 2d 426 (1991), another case involving a Jehovah’s Witness who completed an advance refusal of blood products. In that case, the Michigan Court of Appeals held that the provision of blood products contrary to the advance directive did not constitute an assault because her directive ‘had not been made when her life was hanging in the balance or when it appeared that death might be a possibility if a transfusion were not given’: 475 NW 2d 426 (1991), [150]. By its very nature, however, an advance directive must be given in advance of the medical incident arising. Further, there was no evidence that the maker of the directive contemplated that the directive should only be relied upon in a non life-threatening context.
\textsuperscript{108} [2005] 1 WLR 834.
advance directive not to reinsert the feeding tube after it became dislodged. If they did, then that directive dictated treatment, and health professionals would not be entitled to reinsert the tube. The only issue for determination was whether KH’s prior statements were sufficiently clear to constitute an advance directive. It is surprising, therefore, why, in the context of the discussion of the legal effect of KH’s statements, the Court observed that:

... there has been no case in the books to date in which the court has sanctioned the withdrawal of treatment which is simply providing, in effect, the equivalent of food and drink for anybody other than somebody in a permanent vegetative state (in other words, someone who has no feeling of anything whatsoever).^{109}

This reference to previous case law on withdrawing or withholding artificial hydration and nutrition to individuals in a persistent vegetative state is misguided. This quote appears to be referring to the cases that have authorized withdrawal of artificial nutrition and hydration from individuals in a persistent vegetative state. The legal principle which supports withdrawal in such cases is that the treatment, the provision of artificial nutrition and hydration, is futile. The court appears to be suggesting that withdrawal or withholding may not be futile where the individual is not in a persistent vegetative state. However, such authority should not have been relevant in the case before it. Instead, the court should have considered the cases on advance directives. If KH had given an advance directive that refused artificial hydration and nutrition, the treatment should not have been given. Whether or not the treatment could be regarded as futile would be irrelevant. In other words, cases concerning medical futility raise completely different issues from those about advance directives and, therefore, should have been irrelevant to the court’s consideration of whether, in the case before it, the feeding tube should have been reinserted on the grounds of KH’s prior statements.

(c) Effect of Statutory Reform
The concerns examined above stem from an apparent lack of familiarity of some judicial and quasi-judicial bodies with the relevant legal principles. This position is perhaps not surprising given the relative scarcity of case law in this field, and the urgent context in which many of these cases must be decided. Statutory reform is unlikely to have a direct impact on the familiarity with legal principles in those jurisdictions in which the common law continues to operate. However, legislative enshrinement of an individual’s right to complete an advance

109 Ibid. 839–40.
directive that refuses life-sustaining treatment is a positive step in the direction of clarity and certainty. Legislation removes lingering doubts about the enforceability of advance directives, and clearly articulates the circumstances in which such refusals will be valid and applicable.

VII. Strained Interpretation of Facts

The apparent reluctance of the judiciary to uphold an advance directive that refuses life-sustaining measures is also evident from how some courts interpret the evidence that is presented to them. In some of the cases where following an advance directive would result in a person’s death, the judges have interpreted the facts in a strained way, in an apparent attempt to reach a more ‘palatable’ result. In such cases, courts have made findings of fact that have resulted in the person’s advance directive not being followed. Arguably, such findings are less open on the evidence than findings that the advance directive was valid and applicable to the medical situation that had arisen. This paper suggests that there are two contexts in which courts are likely to interpret the facts in a strained way: in assessing whether the individual had sufficient capacity at the time of completing the advance directive, and in assessing whether the individual would have intended the advance directive to apply in the circumstances that had subsequently arisen.

i. Assessment of Competence

Before considering the approach taken by the courts to assessment of competence, the following observations may be worth considering. The cases in which the capacity of a person is called into question generally involve an unconventional treatment decision being made, and dire consequences flowing from that decision. The capacity of a person is rarely, if ever, judicially considered in cases where a person accepts treatment that is medically indicated. These facts invite speculation on two levels. First, would the cases that were ultimately judicially determined have reached the court if the person had accepted rather than refused treatment? In other words, would the person’s capacity have been called into question? Secondly, if the same person accepted treatment and his or her capacity had been judicially determined, would the court have reached a finding of incapacity? If the first question is answered in the negative, questions may be raised about the medical profession’s ethical stance on establishing and assessing capacity of an adult to consent to treatment. If the second question is answered in the negative, questions must be asked about the legitimacy of the judicial determination of a person’s capacity.
Late last century, there were a number of cases in which the capacity of a pregnant woman to make decisions about medical treatment was called into question.\textsuperscript{110} Such situations commonly arose where the woman wanted to refuse treatment, and that refusal placed the woman’s foetus (and perhaps herself) at risk. In a number of cases, the courts found that the woman lacked the necessary capacity to make decisions about her own health care, thereby enabling treatment to be given on the basis of the woman’s ‘best interests’.\textsuperscript{111} As such, the welfare of the foetus was also safeguarded. Some commentators suggested that courts have been quick to come to this conclusion because the decision made by the pregnant woman is not one that sits comfortably with many individuals in mainstream society and, therefore, the woman must lack capacity.\textsuperscript{112} In other words, the focus has been on the apparent anti-social decision made by the woman that could put her foetus at risk, rather than on an objective assessment of her capacity to come to a decision.

Similar temptations confront courts in the context of an individual who refuses life-sustaining medical treatment in circumstances where most members of our community would accept such treatment. The concern is that there may be a tendency to find that a person lacks


\textsuperscript{111} Four English cases in particular are illustrative. In \textit{Re L (patient: non-consensual treatment)} \[1997\] 2 FLR 837 and \textit{Re MB (Medical Treatment)} \[1997\] 2 FLR 426, the woman was held to lack capacity to refuse a caesarean section because of a needle phobia notwithstanding that the woman in each case did not suffer from any psychiatric condition. In the first instance decision of Hogg J in \textit{St George’s Healthcare NHS Trust v S; R v Collins, ex parte S}, her Honour granted a declaration dispensing with consent to treatment without investigating the extent to which the woman lacked capacity. Her Honour was aware only that the woman had been admitted under the Mental Health Act 1983 for an assessment of her mental and psychiatric condition, and that ‘moderate depression’ had been diagnosed. In \textit{Rochdale Healthcare (NHS) Trust v C}, unreported decision, Johnson J, 3 July 1996, his Honour found that the woman lacked capacity despite the opinion expressed by the obstetrician that she was ‘fully competent’ and without any other medical evidence to the contrary.

\textsuperscript{112} Indeed, this argument was advanced by counsel for the pregnant woman in \textit{Re MB (medical treatment)} \[1997\] 2 FLR 426 at 436, Mr Francis commenting that ‘both in the \textit{Rochdale Healthcare} case and in \textit{Re L} the judge misapplied the C test by evaluating competence by reference to the irrationality of the decision’. See also \textit{R. Bailey-Harris, ‘Pregnancy, Autonomy and Refusal of Medical Treatment’} \[1998\] 114 \textit{The Law Quarterly Review} 550 who comments on the various legal techniques, including finding the woman temporarily incompetent, that are used to authorise a Caesarean section notwithstanding the woman’s refusal; and Maclean, above n. 6 at 3 where the author refers to the ‘fragility of the patient’s self-determination in the face of preserving valued life in the Caesarean section cases’.
capacity because he or she refuses life-sustaining treatment in circumstances where most individuals would act differently.\textsuperscript{113}

The judiciary itself has cautioned medical professionals against assuming incapacity on the basis of a patient making a decision contrary to medical advice. In a case involving a woman with tetraplegia who wished to be taken off artificial ventilation, and where the treating clinicians refused to act on her direction, the court noted and concurred with the following comments of an expert witness:

\dots the clinicians started from the decision made by Ms B, and not from the assessment of her competence. They looked too much at the decision, which was contrary to their advice and which they would not endorse, and not enough at the surrounding circumstances. The clinicians were unable to accept her views and deal with them.\textsuperscript{114}

While these comments were directed at medical professionals, it is submitted that some judges struggle with the same temptation. The argument is that, at the outset the judiciary is drawn to a conclusion that the adult lacks capacity because of the uncomfortable and socially unacceptable treatment choice he or she has made. To support this finding of incapacity, the courts stretch or strain the facts in a way that they would not do if the adult had made a different treatment choice. The following case raises questions about the ability or preparedness of courts to make a finding of capacity in circumstances where that finding may effectively uphold a refusal of treatment that would result in an individual’s death.

\textit{NHS Trust v T (Adult Patient: Refusal of Medical Treatment)}\textsuperscript{115} involved an assessment of T’s capacity to complete an advance directive refusing blood transfusions. T engaged solicitors to draft her advance refusal, and the document contained two reasons for her refusal. First, to use her words:

\dots because I am caught in a vicious circle \dots too difficult for me to continue enduring. I am not aware of when I am cutting myself, and therefore cannot prevent my [haemoglobin] dropping very low periodically. Having a transfusion does not resolve this problem in the long term, only causes stress to myself.\textsuperscript{116}

Secondly, she believed her blood was ‘evil’ and, once the transfused blood mixed with her blood, it also became evil.

There was mixed evidence about T’s capacity. T’s general practitioner had written a letter stating that T understood the nature and effect of the directive, and this letter was attached to the directive. The specialist medical evidence presented at the hearing was divided.

\textsuperscript{113} For a comment on the ease with which judges are able to come to a decision that an individual lacks capacity in the context of the refusal of life-sustaining medical treatment, see also Munby QC, above n. 65 at 325–7.

\textsuperscript{114} Re B (Adult: Refusal of Medical Treatment) [2002] 2 All ER 449 at 468.

\textsuperscript{115} [2005] 1 All ER 387.

\textsuperscript{116} \textit{Ibid.} [8].
Nevertheless, the court held that T lacked capacity to complete an advance directive.

This case was undoubtedly a difficult one. T was suffering from a long-term, probably untreatable, personality disorder which resulted in self-harming behaviour. However, there was consistent and undisputed evidence that T did not want to receive blood transfusions: T consistently made contemporaneous refusals of blood (before being persuaded to accept the transfusion); she attempted to formalize that refusal by approaching solicitors to draft a written advance directive; when given blood contrary to the written advance directive, she again approached her solicitors to write to the hospital to advise them to respect the directive.

Although the medical evidence about her capacity was not unanimous, there was enough evidence upon which the court could have held T to have capacity. The case is consistent with judicial reluctance to uphold a person’s directive where that would result in the person’s death.117

It is interesting to compare this case with the earlier decision of the High Court in Re C (Adult: Refusal of Medical Treatment),118 a case involving a 68-year-old man, C, who was suffering from schizophrenia and who refused to undergo an amputation of his leg despite medical advice that he may die without this procedure. C also suffered from a mental illness and again, as in NHS Trust v T (Adult Patient: Refusal of Medical Treatment),119 the medical evidence was divided about C’s capacity to make a refusal about treatment in the future. Nevertheless, the court held that C had capacity to make an advance decision to refuse the amputation. In coming to its decision, the court seemed to take a different approach to the court in NHS Trust v T in an important respect. In the latter case, the court was heavily influenced by T’s belief that her blood was ‘evil’, a belief integrally related to her mental illness. In contrast, despite C’s oral evidence that he had an international career in medicine during which he had never lost a patient, the court held that C’s delusions did not affect his ability to make a decision about amputation. In other words, there was a greater preparedness to conclude that a person could have capacity to make a treatment decision, despite having a mental illness.120

117 There is evidence of this kind of judicial reluctance in other jurisdictions. See, for example, Fitzpatrick v K [2008] IEHC 104, a case involving the contemporaneous refusal of blood products. In the plenary hearing of the matter in the High Court, Laffoy J held that K lacked capacity at the time she refused treatment, notwithstanding a decision to the contrary by Abbott J on the earlier ex parte application and the contrary evidence of the medical staff at the ex parte application.

118 [1994] 1 All ER 819.

119 [2005] 1 All ER 387.

120 Note the suggestion by Maclean, above n. 6 at 5, that the court may have been more inclined to uphold the advance refusal in this case as C was a ‘dangerous schizophrenic who had stabbed someone and whose life, arguably, was simply a burden for society’.
ii. Assessment of Whether an Adult Intended an Advance Directive to Apply to the Situation that Arose

A medical professional should only comply with an advance directive that refuses life-sustaining medical treatment if the person intended it to apply in the situation that later arose. As part of this assessment, it must be determined whether the terms of the advance directive are sufficiently clear to govern treatment. If there is a reasonable doubt about the person’s intentions, it would be contrary to the law, morality and public policy to refuse treatment and allow the person to die. However, an individual’s autonomy will be undermined if the court places too high a standard on the degree of specificity required for the advance directive to operate.

There is a number of decisions in which the assessments by courts of what the adult intended are difficult to sustain. The first, *W Healthcare NHS Trust v H*,121 involved an application brought by a hospital to reinsert a percutaneous gastrostomy (PEG) tube into a 59-year-old woman, KH, who had suffered from multiple sclerosis for about 30 years. Her family and friends opposed the reinsertion and argued that such action was contrary to the previously expressed views of KH. The woman’s daughter gave evidence that before KH moved into a nursing home, she told her daughter that she did not want to be kept alive by machines. A close friend of KH, Mrs N, also gave evidence. KH told Mrs N repeatedly that she did not ever want to be a burden to her daughters if she could not look after herself. If she had to go to hospital, and the time came when she could no longer recognize the girls, she did not want to be kept alive. KH had reiterated these statements as her condition deteriorated and she became more dependent on the nursing staff. Mrs N had no doubt that, in the current state of health, KH would want to be allowed to die in peace.

Despite this undisputed and apparently credible evidence, the Court of Appeal held that the conversations that KH had with her daughter and close friend did not constitute advance directives relevant to the situation before it. The conversations, according to the court, were not sufficiently clear and referable to the particular circumstance. Although it was conceded that the statements made by KH would be sufficient to refuse life-support machines, they were not specific enough to operate as a ‘direction that she preferred to be deprived of food and drink for a period of time which would lead to her death in all circumstances’.122

It is submitted that the approach of the Court of Appeal was too narrow. There was clear evidence that KH did not want to be kept alive in these circumstances. The fact that she did not specify the

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121 [2005] 1 WLR 834.
medical treatment that she wished to refuse should have been irrele-
vant. If it would be lawful for a competent person to refuse the particu-
lar life-sustaining measure in question, then the fact that that
particular treatment was not specified by KH should not be a reason
for ignoring her advance refusal of treatment.

The English decision of Re T (Adult: Refusal of Treatment),123 al-
though regarded as a case about contemporaneous refusal rather
than an advance refusal, also raised the issue of the scope of the
adult’s refusal, and whether it extended to the medical situation that
arose. T, who had been losing blood since the birth of her child,
indicated to the treating team that she did not want to receive blood
products because she still retained some beliefs of the Jehovah’s Wit-
ness faith. There was uncontested evidence that this statement was
made on a number of occasions, and that T also signed a refusal of
blood form. There was also evidence of conversations between T and
medical professionals that it was unlikely that there would be a need
for a blood transfusion, and of T’s understanding that non-blood
products could be used frequently in substitution for blood. Justice
Ward, at first instance, held that T’s refusal did not apply to the situ-
atation that arose, because she refused blood in circumstances where
she did not believe blood would be needed to save her life. This
decision was upheld by the Court of Appeal. To support his
findings, Ward J relied on evidence of T’s father, not a Jehovah’s Witness, that T
would rather receive blood than die.

The problem with this decision is that there was clear evidence that
T did not want blood products. There was no suggestion in the evid-
ence that T’s refusal was only intended to apply if her life were not at
risk. In fact, at the times the refusals were given, T’s health was seri-
ously compromised and her condition was deteriorating. The court
strained the facts that were before it to justify not following T’s refusal
of treatment.

(a) Effect of Statutory Reform
This section of the paper has examined the approach taken by the
courts when confronted with a case involving the refusal of life-
sustaining medical treatment. The argument is that courts are re-
luctant to make a determination that results in withholding or
withdrawing treatment that is medically indicated. To reach such a
determination, the judiciary sometimes must strain the facts before it.
It is submitted that this reluctance to reach a conclusion that may
result in a person’s death is unlikely to alter as a result of legislative
reform. However, such reform may indirectly address the problem.
The legislation generally requires an advance directive to be in writ-
ing and, in some jurisdictions, requires it to be in a prescribed form.

Further, the Mental Capacity Act 2005 provides that an advance decision will only be effective if the document specifies that the refusal will operate ‘even if life is at risk’. Such requirements may result in clearer instructions being given, and therefore provide less opportunity for the judiciary to read down or misinterpret a person’s instructions.

Nevertheless, there are some issues arising from the Mental Capacity Act 2005 (UK) in terms of whether an advance directive will govern treatment which may require judicial interpretation. One example is section 25(2)(c) which provides that an advance decision is not valid if the individual ‘has done anything else clearly inconsistent with the advance decision remaining his fixed decision’ (emphasis added). The interpretation given to the words ‘clearly inconsistent’ will obviously directly affect the extent to which a person’s decision will operate. Yet, those words are capable of either a wide or narrow interpretation. A further, but related, example is whether the inconsistent action must be taken while the adult still has capacity. The legislation is silent on this point, and arguably either interpretation may be taken. Again, the judicial interpretation of this issue will affect the extent to which a person’s autonomous choice will govern treatment.

VIII. Rhetoric and Approach in Judgments Reveal Preference for the Principle of Sanctity of Life

The focus of the previous three sections of this paper has been on legal errors made, or surprising approaches taken by the courts when deciding whether advance directives should dictate treatment. The submission of this paper is that such errors or unconventional approaches have occurred because (at least some) judges are anxious to decide cases in a particular way, namely that life-sustaining medical treatment should not be withheld from an incompetent individual pursuant to an instruction in an advance directive so that he or she is left to die. This hypothesis is also supported by how the judgments are crafted, including the words and expressions chosen to convey the decision and the reasons for it, and a failure to engage with the importance of the principle of self-determination. The language used by individuals can portray important information about their underlying beliefs and values, and these beliefs and values can and do

124 Mental Capacity Act 2005 (UK), s. 25(5)(a).
125 See, for example, Mental Capacity Act 2005 (UK), Code of Practice in [9.43] which suggests that changes in a person’s personal life, for example, through pregnancy may be sufficient to affect the validity of an advance decision.
126 For a further consideration of this issue, see Maclean, above n. 6.
influence decisions that are made.\textsuperscript{127} It is submitted that this is particularly evident in the cases examined in this paper, the choice of words and expressions conveying the underlying beliefs and values of many judges that the principle of sanctity of life should prevail unless that determination is simply indefensible on the facts before it.

\textit{i. Lack of Discussion of or Emphasis on the Principle of Self-determination}

The advance directive cases contain many examples that indicate the overriding importance placed on the sanctity of life, even in the face of compelling evidence that the individual concerned would rather not be kept alive. The persistent emphasis on the sanctity of life, even while, at times, espousing the rhetoric of the paramountcy of self-determination, subtly suggests that sanctity of life should be the preferred principle where the principles conflict.

The decision of Beach J of the Victorian Supreme Court in \textit{Qumsieh's} case provides such an example. The Guardianship and Administration Board appointed Q’s husband to be his wife’s guardian, and he decided that a transfusion should be given to his wife despite her prior refusal in two formal documents. Beach J of the Victorian Supreme Court was asked to review the board’s decision. In exercising his discretion not to do so, Beach J commented that ‘the order [of the board] was made to save her life and no court would contemplate exercising its discretion to grant a remedy’.\textsuperscript{128} Given that the common law requires a person’s advance directive to prevail over the decision of a substitute decision-maker regarding treatment, this attitude is surprising. Beach J’s comments provide insight into his views, namely that preserving Q’s life was the ultimate goal of the Guardianship and Administration Board’s deliberation, even if her wish was that she not be given a blood transfusion. As Q’s life was saved, she should not be entitled to relief in the form of a review of the board’s decision. Such an approach is consistent with the notion that sanctity of life should prevail over self-determination.

Similar views were expressed by the Court of Appeal of Victoria on appeal.\textsuperscript{129} In dismissing Q’s appeal, the court agreed with the determination of Beach J that ‘no matter of substantial importance was involved’ which required the board’s decision to be reviewed.\textsuperscript{130}

\textsuperscript{127} For a comparative analysis of how the personal views of judges in another medical context, sperm harvesting cases, can affect or inform the outcomes, see M. Leiboff, ‘Post-mortem sperm harvesting, conception and the law: rationality or religiosity?’ (2006) 6(2) Queensland University of Technology Law and Justice Journal 1.


\textsuperscript{129} [1998] VSCA 45.

\textsuperscript{130} \textit{Ibid.} at [19]. There were a number of factors detailed at para. [19] which drew the Court of Appeal to this conclusion including the ‘large number and variety of grounds upon which the appellant was seeking to challenge the Board’s decision, the number of respondents whom the appellant desired to be made parties . . ., the fact that the matter involved an order, now exhausted, made by a body whose
Again, this conclusion is concerning. The comments reveal the same approach taken at first instance. The court did not accept the proposition that the board had sufficient information before it to make ‘alarm bells ring’, and appeared to be satisfied as to how the hearing was conducted by the board. The Court of Appeal judgment did not reveal any concern about the expressed wishes of an individual to refuse treatment being ignored. Implicit in this judgment is the lack of acknowledgement of the paramountcy of the principle of self-determination.131

The language used by the English Court of Appeal in W Healthcare NHS Trust v H132 also conveyed the court’s emphasis on the sanctity of life, without similar regard to self-determination. Here, the court was required to determine whether previous statements made by a 59-year-old woman suffering from multiple sclerosis constituted a common law advance directive. After recounting the undisputed facts, the court set out the relevant law. This description of the law commenced with the following statements:

English law places a very high value on life. The value that English law places on life is now reiterated by art 2 of the European Convention on Human Rights . . . which recited that everyone’s right to life shall be protected by law.133

The court proceeded to describe the law that applies where a patient loses competence and a decision needs to be made about his or her treatment. Reference was made to the two different legal regimes that operate: the best interests test and the substituted judgment test. Interestingly, in the course of this consideration, the court did not emphasize, in addition to ‘life’, that an individual’s right to self-determination was also valued highly under English law, a fact equally relevant to a discussion of this area of law. Such an omission flags this court’s view about the relative importance of the principles of sanctity of life and self-determination.

The language used by Muir J of the Supreme Court of Queensland in State of Queensland v Astill134 also provides insight into his Honour’s perspective of what is important in making determinations about life-sustaining medical treatment. The failure of the court to consider whether the formal document signed by A, a Jehovah’s Witness, in which she refused blood transfusions constituted a common law advance directive, was considered earlier. More generally, in the

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131 See Hamblin, above n. 6, who opines that this case highlights the judicial reluctance to uphold previously stated refusals where that would result in the adult’s death.

132 [2005] 1 WLR 834.

133 Ibid. 837.

134 Unreported decision, Supreme Court of Queensland, Muir J, 18 January 2006.
course of his judgment, Muir J made some comments which suggested that other considerations were more important than following A’s stated wishes. To cite one example:

Were [A] able to be consulted, no doubt she would wish to weigh the impact on her daughter should she die as a result of the accident and should her death result from the lack of a blood transfusion. 135

Muir J seems to be imposing his own view of morality on A. Implicit in his statement is the view that A’s concern for how her daughter may feel should prevail over her earlier, clearly stated wishes regarding treatment. This postulation was in conflict with the evidence of A’s sons who insisted she would not have wanted a blood transfusion. Again, it is concerning that the principle of self-determination was not given the significance that it is accorded under common law. Other factors were regarded as more important on the facts of this case. 136

The recent approach taken by McDougall in Hunter and New England Area Health Service v A 137 is more encouraging. The judgment itself tracked how the principle of autonomy had been judicially recognized in several jurisdictions. There was a clear and repeated reference to the supremacy of this principle over that of the sanctity of life. Indeed, one section of the judgment was headed ‘Supremacy of the individual’s right’.

The emphasis given by McDougall J to the principle of autonomy is encouraging. However, as illustrated by the above analysis, it is not reflective of the approach taken by many of the judges who make determinations about the validity and applicability of advance directives.

**ii. Use of Emotive and Value-laden Words**

There are also examples in the judgments of language which positions those reading the judgments to take a particular view of the facts. This is done subtly, but often powerfully. The courts have used emotive and value-laden language in their inquiry of whether ‘doubt’ exists in an advance directive purporting to refuse life-sustaining medical treatment. At times, courts have summarized or described the evidence about the advance directive in a manner which draws the reader to only one conclusion, that there is some doubt as to whether the individual intended to refuse the life-sustaining medical treatment in the situation that arose. The carefully chosen words used by the judges are crafted to convince the public that the directive given, or words used by the individual in question, could not be regarded as an advance directive refusing treatment. On a more objective view of the evidence, an individual may not consider there to be any doubt in the

136 In addition to how the daughter would feel if A died, the court considered the fact that transfusions had already been given, and the views expressed by all family members: p. 4 of transcript of proceedings.
words used or directive given by the adult. The following example is illustrative of this contention.

In *W Healthcare NHS Trust v H*,[^138] there was undisputed evidence before the court that H did not want to be ‘kept alive by machines’, did not want to be kept alive if she could no longer recognize her girls, and wanted to enjoy only the ‘best quality of life’. Nevertheless, the court held that these statements did not constitute a common law advance directive to refuse the reinsertion of a PEG upon its displacement. The court framed the question to be decided in the following way:

> ... the matter that has to be determined ... is whether ... when she became incapable [H] would choose what would be a distressing form of death by starvation over a period of two to three weeks as opposed to remaining alive, not in pain or particular discomfort, and that she never addressed her mind to that particular choice.[^139]

When phrased in this way, it is not surprising that the court held that she had not intended her previous statements to apply in the medical situation that required determination.

Another example of language which indicates that the courts would rather find that the advance directive refusing treatment did not operate can be found in *HE v A Hospital NHS Trust*.[^140] The court held that the adult did not intend her prior formal refusal of blood transfusions to apply in the circumstances before it. Munby J commented that: ‘... the question of whether an advance directive admittedly made at some time in the past is still valid and applicable may require especially close, rigorous and anxious scrutiny’ (emphasis added).[^141]

Once again, Munby J’s approach can be contrasted with that of McDougall J in *Hunter and New England Area Health Service v A*.[^142] The approach taken by McDougall J and the language that he employs indicate his desire to give effect to the wishes of the individual, despite the potentially significant nature of the outcome:

> ... if there is any real doubt as to the sufficiency of an advance refusal of medical treatment, the court should undertake a careful analysis. But the analysis should start by respecting the proposition that a competent

[^139]: Ibid. at 839.
[^140]: [2003] 2 FLR 408.
[^141]: Ibid. at [25]. For further examples of the use of emotive language used in judgments, see *W Healthcare NHS Trust v H* [2005] 1 WLR 834 at 842 where the English Court of Appeal put the test in the following terms: ‘English law ... places a very heavy burden on those who are advocating a course which would lead inevitably to the cessation of a human life’; and *Werth v Taylor* 475 NW 2d 426 (1991) at 430 where the Michigan Court of Appeals was not prepared to find a medical professional liable for assault even though he knowingly provided a blood transfusion contrary to the patient’s instructions in a formal advance directive. In deciding that the directive was not applicable in these circumstances, the court remarked that ‘[h]er prior refusals had not been made when her life was hanging in the balance’ (emphasis added).
individual’s right to self-determination prevails over the State’s interest in the preservation of life even though the individual’s exercise of that right may result in his or her death. An over-careful scrutiny of the material may well have the effect of undermining or even negating the exercise of that right. It is necessary to bear in mind that not all those who execute advance care directives are legally trained. Their words should not be scrutinized with the care given to a particularly obscure legislative expression of the will of Parliament [emphasis added].

As can be seen, McDougall J’s words are in stark contrast to those used by Munby J in justifying his decision not to comply with a directive refusing treatment.

(a) Effect of Statutory Reform
This section has analysed how judgments have been crafted to support or justify particular judicial outcomes. The approaches taken by judges in communicating their decisions are unlikely to be affected by statutory reform. As flagged earlier in the paper, it is likely to be the case that when adjudicating on matters arising under legislation, outcomes will continue to be driven by views about desirability of advance directives that refuse treatment. It is anticipated, therefore, that judgments will continue to contain emotive language to justify the decision reached.

IX. Conclusions
The sanctity of life is a fundamental principle in a liberal democracy, and this is reflected in the common law that relates to refusing medical treatment. It is also recognized that this principle yields to that of respect for individual autonomy and self-determination in the context of refusing life-sustaining medical treatment either contemporaneously or through an advance directive. To a large extent, this also reflects the position in those jurisdictions in which legislative reform has occurred. In the United Kingdom, for example, an individual can complete an advance refusal of life-sustaining medical treatment that will bind medical professionals. Yet, an examination of the relevant common law cases on advance directives in England and Australia reveals some concerns about the extent to which the established hierarchy of autonomy prevailing over sanctity of life reflects reality, at least in the context of the court room. Further, there is no reason to believe that the approach that will be taken by the judiciary in interpreting statutory provisions will afford autonomy any higher recognition.

The cases dealt with in this paper are difficult. They raise the emotive issues of death and dying, religious values and quality of life, generally in the context of a difficult medical event or situation, and

143 Ibid. at [36]-[37].
sometimes against a backdrop of complex family dynamics. The consequences of the decisions are grave, as a finding of validity and applicability of an advance directive will effectively result in the death of a vulnerable individual. Although there are relatively few cases that have considered the validity and applicability of advance directives, an analysis of those cases reveals some concerning trends for individuals who value the right to determine their own medical treatment. Those trends are reflected in the case law of both England and Australia. This paper argues that, in many of these decisions, the underlying beliefs and views of the particular members of the judiciary who are determining the matter, drive the outcomes. More specifically, despite the clarity of the law on the supremacy of autonomy and self-determination and the rhetoric to that effect in the judgments, some judges simply regard the sanctity of life as the more compelling principle, and allow that principle to dictate the outcome.

This paper does not argue that this approach is taken in all judgments or by all members of the judiciary. Indeed, the approach taken recently by McDougall J of the New South Wales Supreme Court reveals not only a willingness, but a concerted attempt to determine the individual’s wishes, notwithstanding that complying with such wishes would result in his death. Despite this encouraging judgment, the failure to truly embrace principles of autonomy can be observed in the majority of the cases concerning advance directives. There is certainly significant evidence of this trend in many of the decisions on advance directives.

It is, and should be, the case that, where doubt exists, an advance directive refusing treatment should not be followed. In such a situation, it is appropriate for the judiciary to err ‘in favour of life’. However, the case law suggests that many judges are biased in favour of life, even in the absence of doubt, and this bias can and does drive outcomes. The result is dangerous at two levels. First, there are examples where the outcome has not been the desired one for the individual who is the subject of litigation, and whose previous statements about treatment have been ignored. Secondly, there are implications for our society more broadly. The decisions signal a warning to individuals who wish to ensure that their death occurs in circumstances that are acceptable to them: it is unsafe to assume that the judiciary will practise what it preaches, and allow the principle of self-determination to prevail over that of sanctity of life.
# Appendix

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<th>Case</th>
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<td><em>Re C (Adult: Refusal of Medical Treatment)</em> [1994] 1 All ER 819 High Court, Family Division</td>
<td>C was a 68-year-old man suffering from paranoid schizophrenia. He lived in a secure hospital and was serving a seven-year period of imprisonment. C was also suffering from peripheral vascular disease which led to gangrene in his foot. The treating team predicted that unless his leg was amputated from beneath the knee, C had an 85 per cent chance of dying. C did not consent to the amputation and, following more conservative treatment, C’s condition improved. C’s condition placed him at risk in the future, and the hospital indicated that amputation may be necessary. C sought an injunction restraining the hospital from carrying out an amputation without his express written consent.</td>
<td>The injunction was granted. It is implicit in this decision that the adult’s prior refusal constituted a valid advance directive and, unless the adult’s circumstances altered in the future, should be followed.</td>
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<td><em>Re AK (Medical Treatment: Consent)</em> [2001] 1 FLR 129 High Court, Family Division</td>
<td>AK was a 19-year-old man suffering from motor neurone disease, and made an advance directive at an advanced stage of the disease. He was on a ventilator and could only communicate through moving one eyelid to indicate ‘yes’ or ‘no’ to questions put to him. His instructions were that his ventilation should cease two weeks after he could no longer communicate. The hospital sought a declaration that it would be lawful for the treating team to follow AK’s instructions.</td>
<td>The adult’s communication was held to constitute an advance directive which was valid and applicable, and should be followed.</td>
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<td><strong>HE v A Hospital NHS Trust [2003] 2 FLR 408</strong></td>
<td>AE, although born a Muslim, was raised by her mother as a Jehovah’s Witness. When she was 24, AE signed an advance directive refusing blood products. This directive also contained a clause providing that the directive could only be revoked in writing. Almost two years later, she saw a doctor about her heart disease. In contemplation of surgery, she advised her doctor that she did not wish to have blood products. Five months later, AE became seriously ill and was rushed to hospital. The hospital advised that she needed a blood transfusion to save her life, but her mother and brother said that AE would not want to receive a transfusion. AE’s father brought an application to the court seeking an order that the advance directive no longer applied and directing the hospital to carry out the transfusion.</td>
<td>The adult’s advance directive was held not to be valid and applicable, and should not be followed.</td>
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<td><strong>KH v H [2005] 1 WLR 834</strong></td>
<td>KH was a 59-year-old woman who had suffered from multiple sclerosis for about 30 years. She was being kept alive through a percutaneous gastrostomy (PEG) tube which had become dislodged. A decision had to be made whether it should be reinserted. The hospital brought an application to court seeking approval to reinsert the PEG</td>
<td>The appeal was dismissed. The adult’s previous statements were held not to constitute a valid and applicable advance directive and should not be followed.</td>
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Case

NHS Trust v T (Adult Patient: Refusal of Medical Treatment) [2005] 1 All ER 387 High Court, Family Division

Facts

tube. There was evidence before the court that KH previously directed that she did not wish to receive treatment in these circumstances. The hospital’s application was granted at first instance, and KH’s brother and one of her daughters appealed against that decision.

T was a 37-year-old woman who suffered from a borderline personality disorder. She had a long history of self-harm by cutting herself and bloodletting. T was frequently admitted to hospital after such incidents and given life-saving blood transfusions. She often refused such treatment initially, but was always subsequently persuaded by health professionals to accept the transfusion. In January 2004, T approached solicitors to assist her to draft an advance directive refusing blood transfusions to operate in any subsequent hospital admission. Despite this advance directive, T was provided with a further transfusion in April of the same year, the hospital receiving authorization from a duty judge to do so. Following release from the hospital, T again approached her solicitor who wrote to the hospital advising it that T stood by her advance directive. The hospital applied to the Family Division for directions.

Decision

The adult’s advance directive held not to be valid, and should not be followed.
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<td>Qumsieh’s case</td>
<td>Q, a Jehovah’s Witness, was admitted to hospital for the birth of her first child. She had earlier signed a document headed ‘Advance Medical Directive’ in which she refused blood products, and signed a form consenting to the administration of anaesthetics but added ‘with the exception of blood transfusion or blood products’. Complications occurred following the delivery of her child, and Q needed a blood transfusion to save her life. Given her prior refusal of blood products, the hospital refused to provide her with a transfusion. With his wife’s death imminent, her husband, also a Jehovah’s Witness, sought legal advice and an application was brought to the Victorian Guardianship and Administration Board on the same day.</td>
<td>The board appointed the adult’s husband as decision-maker (as the delegated guardian of the Public Advocate) and the husband consented to the transfusion. The effect of the board’s decision was that the adult’s advance directive was <strong>not followed</strong>.</td>
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<td>Supreme Court of Victoria, Unreported decision, Supreme Court of Victoria, Beach J, 7 May 1998.</td>
<td>The court declined Q’s application to review the decision of the board.</td>
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<td>Supreme Court of Victoria, Court of Appeal [1998] VS CA 45</td>
<td>The court dismissed Q’s appeal against the decision of Beach J.</td>
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<td>High Court of Australia Qumsieh  v Pilgrim M98/1998, 29 October 1999, 11 February 2000.</td>
<td>The court declined leave to review the decision of the Court of Appeal</td>
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<td><strong>State of Qld v Astill</strong> Unreported decision, Supreme Court of Queensland, Muir J, 18 January 2006.</td>
<td>A, a Jehovah’s Witness, had been involved in a serious car accident, the car having been driven by her daughter. A was given a blood transfusion at the scene and transported to hospital where further transfusions were administered. On learning that A had completed an advance directive refusing blood products, the hospital brought an application to the Supreme Court seeking an order to provide her with blood products.</td>
<td>The court ordered that the treating medical practitioner be entitled to provide the adult with a blood transfusion if that was necessary to save her life. The effect of the decision was that the adult’s advance directive was <strong>not followed</strong>.</td>
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<td><strong>Hunter and New England Area Health Service v A</strong> [2009] NSWSC 761 Supreme Court of New South Wales</td>
<td>A, a Jehovah’s Witness, completed a document called a ‘worksheet’ in which he expressly refused the medical treatment of dialysis. About a year later, A was admitted to the emergency department of the hospital suffering from septic shock and respiratory failure. A’s condition deteriorated and he was being</td>
<td>The court held that the document constituted an advance directive and should be <strong>followed</strong>.</td>
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## Case Facts Decision

kept alive by mechanical ventilation and kidney dialysis. The hospital brought an action to determine whether the document constituted a valid advance directive and should be followed.