

ACHIEVING AUTONOMY in end-of-life decision-making

By Sonja Brown

Good end-of-life care embraces two fundamental elements: respect for an individual's choices; and the provision of medical care that is in the best interest of the patient, assessed by medical professionals in fulfilment of their legal and ethical duties to the patient.

Typically, these principles work together and patients are provided with the most dignified and comfortable death possible in the circumstances. However, on occasion, there are disagreements between patients, medical professionals and substitute decision-makers about the appropriate course of patient care. In these cases, the law provides a decision-making hierarchy. Primacy is given to patient autonomy.

Many Australian states and territories have enacted legislation regulating decision-making for incompetent adults.¹ Unfortunately, that legislation is not uniform between the jurisdictions, and the legislation itself is

complicated in its application to many real-life situations. For these reasons, it can be difficult for medical professionals and substitute decision-makers to understand the legislative requirements, particularly in the stressful and emotional circumstances of end-of-life decision-making. A summary of the recent legislative developments is set out below.

This article outlines three recent cases that consider the right of competent adult patients to refuse treatment, even where that direction will lead to the patient's death, and discusses the benefits of advance care planning. These cases show that, although the dominance of the patient autonomy principle is well-established, there may be some difficulties in identifying a truly autonomous choice. >>

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RECENT LEGISLATIVE DEVELOPMENTS

Most states and territories now have legislation setting out the requirements, status and implementation rules for advance health directives. On 15 February 2010, amendments to the *Guardianship and Administration Act 1990* (WA) commenced. It provides a legislative basis for advance health directives in WA. Statutory regimes now operate in Queensland, Victoria, WA, SA, the ACT and the NT.

Reviews of guardianship legislation are also currently underway in Queensland and Victoria. The Queensland Law Reform Commission (QLRC) is undertaking a review of the law in relation to the general principles set out in legislation, the scope of substituted decision-making, the role of the support network, adequacy of investigative powers, health and special health matters, and other miscellaneous matters, under the *Guardianship and Administration Act 2000* (Qld) and the *Powers of Attorney Act 1998* (Qld). The QLRC's report was due in December 2009, and is expected to be published in the near future. On 19 June 2009, the Victorian attorney-general announced a major review of Victoria's guardianship laws. That report is due by June 2011.

There have also been some structural changes to the tribunals that hear matters relating to decision-making for incompetent adults. In 2009, the Guardianship and Management of Property Tribunal in the ACT and the Guardianship and Administration Tribunal in Queensland, were incorporated into the ACT Civil and Administrative Tribunal (ACAT) and the Queensland Civil and Administrative Tribunal (QCAT), respectively.

DETERMINING CAPACITY

The common law in Australia recognises the right of competent adults to make their own decisions in relation to what healthcare they receive.² Competent adults have a right to choose not to have treatment, even where the decision will lead to their death. Several difficulties arise in practice. The first is a clinical issue; namely, determining whether the patient is in fact competent to make the decision purported to be made, and that the decision is made freely without undue influence from any third party. Secondly, where the patient has given a valid direction, the medical professional must decide whether it applies to the particular situation that has arisen. This reinforces the importance of clear directions. The final issue considered here is whether a certain level of information must be given to a patient prior to a valid direction being made.

There is a presumption of capacity – whereby every adult is presumed to have capacity to consent or refuse medical treatment – unless and until that presumption is rebutted. Capacity means that the person is capable of understanding the nature and effect of decisions about the matter, freely and voluntarily making such decisions, and communicating those decisions in some way.³ Provided that there is no basis to suspect that the patient did not have capacity at the time of making the relevant decision, the law requires that the patient's decision be respected. Importantly, this does not permit medical professionals to take active steps to hasten the death of a patient (commonly known as euthanasia).

Capacity is properly characterised as existing on a continuum, dependent on the time at which capacity is being determined and the kind of decision being made. For example, a person may have capacity to give consent to the setting of a broken arm, but not for a decision to withhold life-sustaining measures. Further, a particular patient's capacity to consent may fluctuate over time, with a patient experiencing periods of lucidity during which they may have capacity to make certain decisions. This means that determining capacity for a certain decision at a certain time can be difficult in the clinical context. In complex cases, where the decision being made has grave consequences, it is prudent to engage a specialist psychiatrist to assess patient capacity.

REFUSAL OF TREATMENT BY COMPETENT ADULT PATIENTS

Several recent cases show the complexities that can arise in implementing the seemingly straightforward principle that competent adults are able to refuse medical treatment. Interestingly, two of the cases deal directly with the level of information that the patient must have in order to make a valid decision.

*Hunter and New England Area Health Service v A*⁴

In this case, the NSW Supreme Court considered the right of a competent adult to refuse medical treatment and whether the advance health directive was a valid exercise of that right. A, a Jehovah's Witness, had made an advance health directive refusing dialysis. McDougall J was satisfied that A had capacity to refuse dialysis at the time that he made the advance health directive, and that there had not been any undue influence in his making of that decision. In holding that the document constituted a valid advance health directive under common law, his Honour made some important comments about the supremacy of patient autonomy. Interestingly, McDougall J considered whether an advance health directive was valid if the adult did not receive 'adequate information' before completing the directive, and held:

'A consent that is based on misleading information is clearly of no value; and a consent based on insufficient information is not much better. But once it is accepted that religious, social or moral convictions may be of themselves an adequate basis for a decision to refuse consent to medical treatment, it is clear that there is no reason that

a decision made on the basis of such values must have taken into account the risks that may follow if a medical practitioner respects and acts on that decision.⁵

McDougall J also cautioned against the 'over-scrutiny' of directions in an advance health directive, on the basis that such a course could undermine the right of the patient to exercise their autonomy.

Although some have cited the comments of McDougall J as having general application, such that disclosure of information is not required for an advance health directive to be valid, this appears to take his Honour's reasons beyond their context. McDougall J was dealing with a situation where a patient was unconscious at the time the treatment was to be withdrawn, and where the patient had made a decision on a religious basis, which would (presumably) not have been altered by a better understanding of how dialysis works or the risks and benefits of that treatment. This is quite different to a circumstance where a patient makes a decision to refuse dialysis on the basis of an incorrect understanding of the risks and benefits of that procedure, and the patient has capacity at the time of refusing the treatment. Indeed, McDougall J conceded that consent based on misleading or insufficient information is of little or no value. The difficulty is that patients may make advance health directives without expressing reasons for their decision, and so any fundamental misunderstanding of fact will often not be apparent. No investigation of the basis of the decision contained in an advance health directive is required by the legislation.

Brightwater Care Group v Rossiter⁶

In this case, the Supreme Court of WA considered the legal obligations of a medical service-provider, which had assumed responsibility for the care of a competent patient. Mr Rossiter suffered from quadriplegia and was entirely dependent on the staff of Brightwater Care Group for the provision of the necessities of life. He was not, however, terminally ill. Due to his physical disability, Mr Rossiter was unable to take any action to bring about his own death. He directed staff to discontinue the provision of nutrition and hydration and he was aware that this would lead to his death by starvation. Martin CJ referred to *Hunter and New England Area Health Service v A*, and stated:

'McDougall J (at [28]-[30]) rejected the notion that a refusal to consent had to be informed to be effective in the context of an advance directive given by a person who, at the time of the court hearing, lacked the capacity to receive further information or make any further decision.'⁷

His Honour held that the circumstances of Mr Rossiter were quite different because he was able to receive and consider more information and to make informed decisions after weighing that information.⁸ In comparing the obligation of a health professional to obtain informed consent for treatment to be provided to that where consent to treatment is being refused, Martin CJ stated:

'[w]ith respect to McDougall J, in the circumstances of this case, where it is perfectly feasible to ensure that Mr Rossiter is given full information as to the consequences

of any decision to discontinue treatment before he makes that decision, I can see no reason why his medical service providers should not be under a similar obligation.'⁹

Martin CJ ultimately held that Mr Rossiter had the right to determine whether or not he would continue to receive the services, but that Brightwater Care Group had a duty to ensure that Mr Rossiter was offered full information on the precise consequences of any decision to discontinue the provision of nutrition and hydration, prior to him making that decision.

It is well settled that a medical professional must inform the patient in broad terms of the nature of the procedure to be carried out, to defend an action in the tort of battery, and must provide full information, including the risks and benefits, to defend an action in negligence. Logically, the decision-making process incorporating considerations of the risks and benefits of treatment is the same, whether the ultimate decision is to consent to treatment or to refuse the treatment. This is fundamental to the decision in *Brightwater Care Group v Rossiter*. It follows that, although it is proper that a patient who is apprised of the relevant information may validly refuse consent on any grounds, this scenario is not to be confused with a case where a patient makes a direction under a fundamental misunderstanding of what is involved in the treatment or the likelihood of success of a treatment. Carrying out such a direction is, in fact, not consistent with the respect of patient autonomy. It is crucial >>

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for patients to have the necessary information in order for them to make an autonomous choice. However, once made, the autonomous choice must be respected, even if it appears to be illogical or unwise.

Australian Capital Territory v JT

In *Australian Capital Territory v JT*,¹⁰ Higgins CJ of the Supreme Court of the ACT dismissed an application for a declaration that it was lawful for medical professionals to desist from providing distressing force-feeding medical treatment to a 69-year-old man (JT) who was suffering from paranoid schizophrenia, characterised by religious obsessions that demanded that he fast himself to the point of starvation. In relation to the approval provided by the Ethics Committee for the withholding of the treatment, Higgins CJ stated: 'That is an outrageous approach to ethical standards which require a free and informed consent before a course involving such grave risk as premature death is adopted.'¹¹ The Court referred to *Brightwater Care Group v Rossiter*, and stated:

'[t]hat case, of course, is fundamentally distinguishable from the present. The patient here lacks both understanding of the proposed conduct and the capacity to give informed consent to it.'¹²

Interestingly, the Court noted that there had been remissions in JT's obsessions, but did not specifically consider whether JT had capacity during those periods to refuse treatment. This may reflect the fact that there is a reluctance to accept all reasons given by patients for withholding treatment, and poses a challenge for medical professionals to respect autonomous choices where patients are competent but have illogical views.

Respecting patient autonomy

The law does not require a medical professional to investigate whether a particular patient had sufficient information to make a decision recorded in an advance health directive where that patient is unconscious on arrival at the hospital. Requiring this level of investigation might be considered unworkable and would detract from the certainty achieved through the completion of an advance health directive. The cases of *Hunter and New England Area Health Service v A* and *Brightwater Care Group v Rossiter* can be distinguished on the critical ground of the patient's state of consciousness at the time that the treatment is to be withdrawn or withheld. This raises the question of how the law is able to protect patients who make decisions before they present to a medical professional in an incapacitated state.

The involvement of medical professionals in the completion of advance health directives and the regulation of the form and content of such directives is an effective way to build a safeguard into the advance care planning process. In those states and territories where the certificate of a medical professional is required to prepare a valid advance health directive, the patient has the opportunity to speak with a medical professional about their decisions. This provides some comfort that grave decisions are not being made on the basis of fundamental misunderstandings about the nature and potential outcomes of the treatment to be refused.

These protections should be embraced in the legislative schemes and the clinical environment.

In cases where patients are competent at the time of presenting to a hospital or during their admission, open and ongoing communication about treatment options should be encouraged and documented. This provides control to patients and protects against decisions being made on the basis of misunderstandings of fact.

THE BENEFITS OF ADVANCE CARE PLANNING

The process of advance care planning itself has been shown to improve end-of-life care and patient and family satisfaction, while reducing stress, anxiety and depression in surviving relatives.¹³ In cases where patients are competent at the time of their admission to hospital, particularly where the prognosis is poor, communication with them and their families about the available options and completion of advanced health directives is a highly effective risk management strategy, not to mention clearly beneficial for patients and their families and friends.

In April 2010, Queensland Health commenced a public education campaign in advance care planning, with the slogan: 'Think now. Plan sooner. Peace of mind later.' The program is designed to get people thinking about their wishes for care in the future, and to talk about those wishes with others and/or record them in one of the recognised forms. These types of initiatives are useful in encouraging open communication about difficult topics.

CONCLUSION

The best management of end-of-life decision-making involves clear and open communication between medical professionals, patients and their friends and families. To this end, the focus of medical professionals should be on engaging the interested parties in discussions about care. This approach is extraordinarily effective, with very few matters needing to come before tribunals or courts.

Ultimately, it is important to support patients in decision-making by providing information and facilitating autonomous choices. Where the choice made is autonomous, it should be respected. ■

Notes: **1** A good summary of the relevant legislation as at June 2008 is contained in C Stewart, 'Managing Death and the Law' (2008) 86 *Precedent* 4. **2** There are some restrictions on this right. Importantly, a patient cannot compel a medical professional to provide treatment that the medical professional considers is not in that patient's best interest. **3** See, for example, *Powers of Attorney Act 1998* (Qld), sch 3. **4** [2009] NSWSC 761. **5** [2009] NSWSC 761 at [30]. **6** [2009] WASC 229. **7** [2009] WASC 229 at [28]. **8** [2009] WASC 229 at [29]. **9** [2009] WASC 229 at [30]. **10** [2009] ACTSC 105. **11** [2009] ACTSC 105 at [17]. **12** [2009] ACTSC 105 at [29]. **13** KM Detering et al, 'The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomised Controlled Trial' *British Medical Journal* 2010; 340: c1345.

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