Refusing medical treatment IN ADVANCE

By ROSHAAN SINGH RAINA

An individual's right to determine their fate was tested in the cases of Hunter and Brightwater.

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THE CONFLICTING INTERESTS of a competent adult's right to self-determination (the right to control one's own body), and the interests of state or private institutions in preserving the lives of individuals under their care, have now moved to the forefront of health law.

This contest has been considered in different capacities in the recent decisions of *Brightwater Care Group (Inc) v Rossiter*[1] and *Hunter and New England Area Health Service v A*,[2] both handed down in August 2009.

Advance care directives

A person may make an advance care directive which specifies the medical treatment they wish (or do not wish) to receive, such as blood transfusions. If the advance care directive made by a capable adult is clear and unambiguous, and extends to the situation at hand, it must be respected.

By their very nature, advance care directives are prepared in relation to future medical treatment. The scenario in *Hunter* provides a factual matrix which is becoming increasingly common. Health professionals are encouraged[3] to turn to the courts for judicial declarations on the applicability and validity of such directives. There is a particular reliance on the common law in this regard: the use of advance care directives had not been given legislative standing in NSW at the time of the writing of this article.

Case summary – Hunter

Mr A, a Jehovah's Witness, had been admitted to the emergency department in a critical state with a decreased level of consciousness. His condition later deteriorated, resulting in renal failure. He was kept alive by mechanical ventilation and kidney dialysis.

The hospital later became aware of his advance care directive prepared a year earlier, which indicated Mr A would refuse dialysis. The absence of dialysis would undoubtedly hasten his death. The hospital sought a judicial declaration to determine the validity of the advance care directive given by Mr A.

The court noted that advance care directives are not always executed by legal professionals, and that "the court must feel a sense of actual persuasion that the individual acted freely and voluntarily, and intended his or her decision to apply to the situation at hand".[4]

The court reaffirmed that a direction to refuse medical treatment (by a patient with capacity) did not have to be sensible, rational or well-considered.[5] Even a direction lacking any apparent justification must be respected, regardless of how mistaken[6] such a choice may appear to others.

Unless the presumption of capacity is rebutted, or there is evidence which would result in a vitiation of that consent (for example, undue influence; the terms of consent were ambiguous; or no proper explanation of the medical treatment was provided despite adequate opportunity to do so), the individual's right must be respected.

The individual's right to self-determination may potentially be overridden judicially in exceptional circumstances to deal with a widespread and dangerous threat to the population at large.[7]

Treatment may also be administered when it is not practicable to obtain consent.[8] This 'emergency principle' only applies where there is a reasonable basis[9] for doubting the validity and applicability of an advance care directive. These principles extend beyond medical practitioners and apply to anyone who may administer medical treatment, such as ambulance officers and paramedics.[10]

In *Hunter*, the Supreme Court of NSW declared the advance care directive was

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valid. Justice McDougall clarified from the outset that this was not a case concerned with the 'right to die' – but the recognition of Mr A's right to refuse medical treatment.[11]

Any treatment provided to Mr A contrary to his advance care directive would create a tortious liability.[12] The tort of battery has traditionally protected the individual from unwanted physical interference[13] and would hold treating health professionals liable at tort for their unauthorised conduct,[14] despite their justifiable belief that such conduct was necessary to preserve the patient's life or health.[15]

Case summary – Brightwater

Brightwater was decided in Western Australia on 14 August 2009, not a fortnight after *Hunter*.[16] Mr Rossiter had suffered a number of serious injuries over 20 years in four notable incidents, the last of which culminated in spastic quadriplegia.

In the course of his medical treatment, he was eventually transferred to the Brightwater facility which provided residential care for disabled individuals. Mr Rossiter had been a resident at that facility since 4 November 2008.

Mr Rossiter was unable to take nutrition or hydration orally on account of his quadriplegia. The nutrition and hydration required was provided by way of a percutaneous endoscopic gastronomy (or PEG) tube, which had been surgically inserted directly into his stomach.

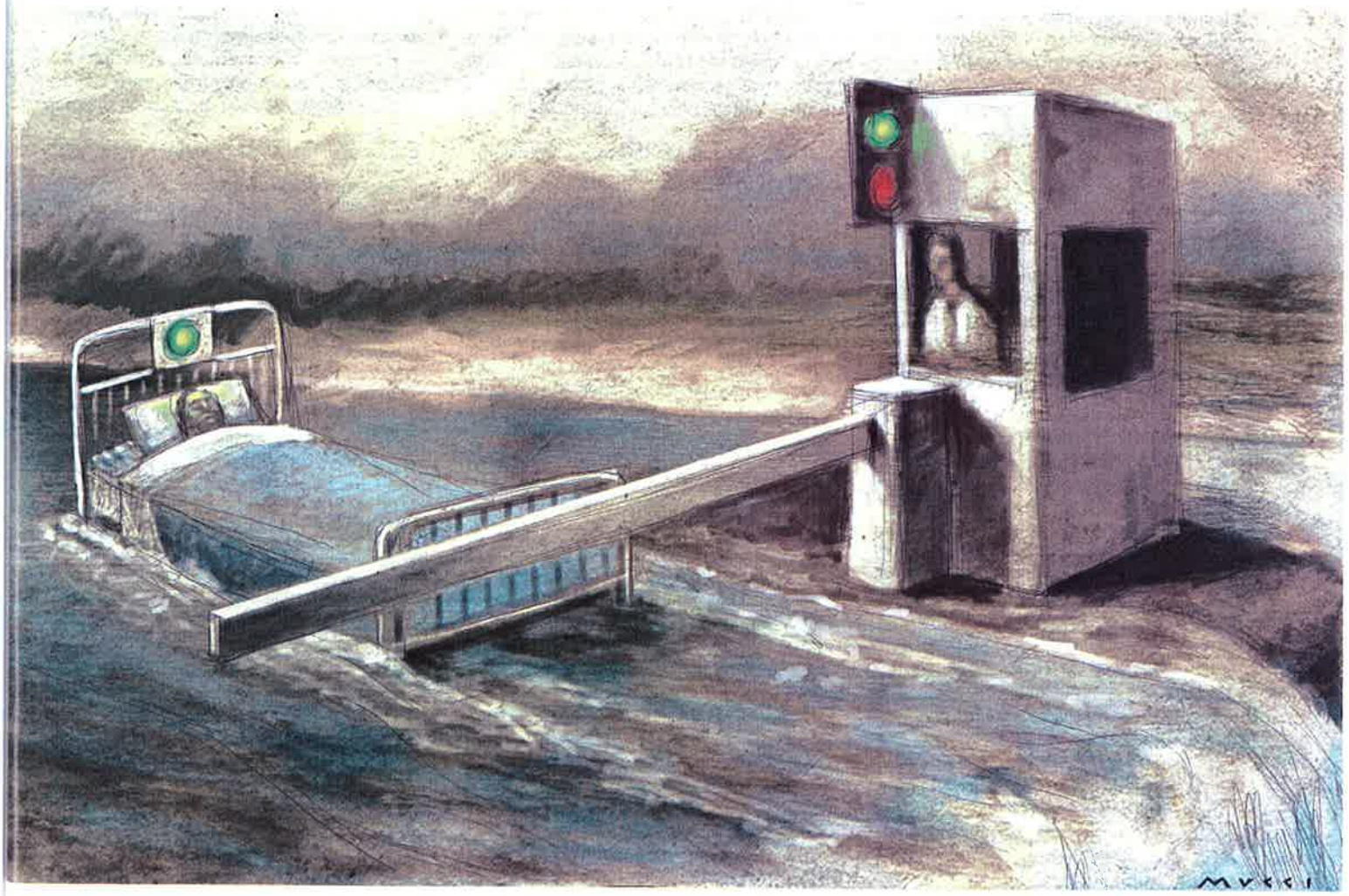
> "Allowing an individual to refuse medical treatment which results in death does not equate to a judicial step towards the legalisation of euthanasia."

Despite his physical disabilities, Mr Rossiter was not terminally ill, nor was he dying. If the services provided by Brightwater had been continued, he would have lived on for many years. His mental faculties remained intact. The court noted he was capable of making reasoned decisions[17] in respect of his future medical treatment.

Mr Rossiter had "clearly and unequivocally"[18] indicated to the representatives of Brightwater that he wished to die on many occasions. As he lacked the physical capacity to bring about his own death, he directed the staff at Brightwater to discontinue the provision of nutrition and general hydration[19] through the PEG. Mr Rossiter was aware[20] that he would die from starvation if nutrition and hydration were no longer administered through the PEG.

A guardianship order previously in place had been revoked prior to the Supreme Court proceedings. Therefore, there was no question of other people making decisions on Mr Rossiter's behalf. Both Brightwater and Rossiter sought judicial declarations as to their respective rights and obligations.

In particular, Brightwater sought relief in respect of potential criminal prosecution[21] that might arise as a result of compliance with Mr Rossiter's directions. While this article will not delve into a detailed analysis of those statutory provisions, it is notable that this particular issue was



resolved in favour of the right to self-determination.[22]

Hunter distinguished

In the case of an unconscious patient, the two fundamental questions which lie at the heart of every contentious advance care directive rejecting specific life-saving medical treatment are:[23]

- ❑ Was the directive valid at the time it was expressed?
- ❑ Does the directive reflect the individual's settled intention in the emergency (which has arisen) that their life may be forfeited by their advance care refusal?

An advance care directive is a clear attempt by the individual to exercise their ultimate right to choose how to live – an expression of an individual's free will. It is an instrument which serves to speak in circumstances where the patient cannot (presumably because of illness or injury).[24]

Chief Justice Martin distinguished *Hunter* on the extent to which an individual's decision to refuse consent to treatment must be an informed decision,[25] noting that Mr Rossiter had the capacity to receive and consider the information he was given, and to make informed decisions after considering that information.[26] His Honour expressed doubts as to whether Mr Rossiter had been fully informed on the physiological consequences of starvation and included, in the declaration, a discreet requirement that Mr Rossiter be given advice by "an appropriately qualified medical practitioner as to the consequences which would flow".[27]

Shortly after judgment was handed down, Mr Rossiter developed a chest infection. He refused medical treatment in respect of this infection, and his health steadily declined. Just five weeks after the decision in *Brightwater*, he eventually slipped into unconsciousness and died.[28]

A glaring hypothetical question arises in respect of his directive: what if Mr Rossiter had lapsed into a coma prior to obtaining further medical advice, as required by the court?

And further, could Mr Rossiter's directive have formed the basis for his advance care in such a situation, on the basis that such consent or refusal to medical treatment need not be in writing, and could be inferred from the patient's conduct in the context of the surrounding circumstances?[29] One would trust that substance would take precedence over form in this regard.

It flows from the reasoning of Chief Justice Martin that if Mr Rossiter had lapsed into a coma at the conclusion of the proceedings prior to receiving the 'requisite' advice by a medical practitioner, then Mr Rossiter's unequivocal intention in relation to his future medical care could not have been fulfilled.

In my opinion an individual's consent to or refusal of medical treatment should not, *as a matter of course*, need to be predicated with qualified medical opinion before being judicially validated. To require otherwise would only serve to frustrate the social, religious or moral values which underpin the direction in question.[30]

"The doctrine of 'informed consent' is important to distinguish from that of 'informed refusal'."

The extent of Mr Rossiter's knowledge regarding the physiological consequences of the withdrawal of treatment should not have been called into question and made conditional upon obtaining further medical advice. Direct medical evidence[31] had already established that Mr Rossiter exhibited a level of capacity which had been commensurate with the gravity of the decision he purported to make,[32] and salient facts indicated that Mr Rossiter had thoroughly comprehended the consequence of his decision.

Consider his unwavering[33] constancy, which evinced a settled intention.[34] Consider also the specificity of Mr Rossiter's direction.[35] This was not a case of an uninformed blanket denial of certain forms of medical treatment rooted in religious conviction.[36] That his decision was contrary to what may be expected to be the decision of the vast majority of adults should have only been relevant if there were other reasons which rebutted the presumption of his capacity.[37] Only then should the nature of his directive or the terms in which it was expressed be allowed to tip the balance.[38] An example of such a vitiating factor would be undue influence.[39]

In circumstances where it is practicable for a health professional to obtain consent to treatment, the patient need only be informed in broad terms of the procedure.[40] Such consent may need to be revisited in the event that the factual situation falls outside the scope of the consent, or if the assumption upon which it is based is falsified.[41]

The doctrine of 'informed consent' is important to distinguish from that of 'informed refusal'. However, the question of whether a person making an 'informed refusal' requires a higher level of knowledge of the consequence of their decision does not[42] necessarily arise in the case of advance care directives.

Advance care directives need no rational basis, particularly where adequate information[43] has been provided:[44] "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 ... [this] is so a fortiori where there is no discernible rational basis for the decision.*" [emphasis added]

However, the right to self-determination, in this very specific context, is a double-edged sword. It also underpins

ENDNOTES

1. *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229.
2. *Hunter and New England Area Health Service v A* [2009] NSWSC 761.
3. *Re T* [1992] EWCA Civ 18 at [37].
4. Above, n2, at [37].
5. *Re T* [1992] EWCA Civ 18 at [30] and [39]; *Sidaway v The Governors of Bethlem Royal Hospital* [1985] UKHL 1 at 28.
6. *Malette v Shulman* [1991] 2 Med.L.R. 162 at [19].
7. Above, n2, at [17].
8. Id at [31].
9. Id at [34].
10. Id at [41].
11. Id at [4].
12. Above, n6, at [13].
13. Id at [17].
14. This is subject to the 'emergency principle' where a patient is incapable of either giving or withholding consent.
15. Above, n6, at [19].
16. The decision in *Hunter* was handed down on 6 August 2009.
17. Above, n1, at [14].
18. Id at [11].
19. General hydration was taken to exclude the necessary hydration to dissolve painkillers, the prescription of which Mr Rossiter wished to be maintained throughout the refusal of nutrition and hydration.
20. There was an ancillary issue regarding the degree of advice given to Mr Rossiter on the effects of starving to death. This was addressed by Chief Justice Martin in his Honour's declaration.
21. Importantly, Chief Justice Martin noted that declarations are not generally made in respect of the criminality of conduct which has already taken

the established legal requirement that the informed consent of the patient is required before any medical treatment can be undertaken lawfully.[45]

Notably, the very same supremacy which underpins that right is also the source of a health professional's duty to inform. Lord Scarman elucidated this in Sidaway:[46] "The doctor's duty arises from his patient's rights. If one considers the scope of the doctor's duty by beginning with the right of the patient to make his own decision whether he will or will not undergo the treatment proposed ... the proper implementation of [that] right requires that the doctor be under a duty to inform his patient of the material risks inherent in the treatment."

Walking the line

Chief Justice Martin, in what appears to be judicial de rigueur in such matters, opened his judgment with the following: "it is important to emphasise at the outset what this case is not about. It is not about euthanasia. Nor is it about physicians providing lethal treatments to patients who wish to die. Nor is it about the right to life or even the right to death ..."[47]

His Honour later reiterated the illegality for any person, including a health professional, to administer medication for the purpose of causing or hastening the death of another person.[48]

His Honour declared that if Mr Rossiter maintained his direction (for the refusal of general hydration and nutrition), even after receiving qualified medical advice regarding the consequences of such treatment (that is, starvation), then Brightwater could not lawfully continue to administer nutrition and hydration unless Mr Rossiter revoked that direction. Simply put, the direction sought by Mr Rossiter was within his rights to request.

While *Hunter* and *Brightwater* can be factually distinguished on the critical ground of the patient's presenting state of consciousness, both cases recognise the following right: "[that a] competent adult is generally entitled to reject a specific treatment or all treatment, or select an alternate form of treatment, even if the decision may entail risks as serious as death and may appear mistaken in the eyes of the medical profession or of the community ... it is the patient who has the final say on whether to undergo the treatment".[49]

The traditional concept of euthanasia is often associated with the administration of treatment to end the life of an individual (that is, lethal injection) and not the passive act of the withdrawal of treatment. Allowing an individual to refuse medical treatment which results in death does not equate to a judicial step towards the legalisation of euthanasia.

Instead, both *Hunter* and *Brightwater* rightfully reaffirm the individual's right to self-determination and, to a thinly veiled extent, the right to dictate the terms of one's departure. ❑

place – to do so would usurp the criminal process and the possible role of the jury.
22. Above, n1, at [55]: it was declared that the provision of palliative care to Mr Rossiter would not result in criminal liability, despite the fact that the need for palliative care resulted from the direction which withdrew treatment to sustain his life.
23. *Re T* [1992] EWCA Civ 18 at [19], citing Justice Donnelly at first instance in *Malette v Shulman* (1990) 67 DLR (4th) 321.
24. Above, n6, at [13].
25. Above, n1, at [28].
26. Id at [29].
27. Id at [58].
28. Mr Rossiter died on 21 September 2009.
29. Above, n3, at [5].
30. Above, n2, at [28].
31. Above, n1, at [23].
32. Above, n3, at [28].
33. According to several media sources, Mr Rossiter reportedly communicated his request in relation to nutrition and general hydration to the Brightwater Care Group over 40 times prior to the hearing on 14 August 2009. The author believes that this frequency is significant, given that Mr Rossiter had only been a resident at the Brightwater facility since 4 November 2008.
34. Above, n23.
35. Above, n19.
36. Above, n6, at [13].
37. Above, n3, at [30].
38. Ibid.
39. As stated in *Re T* [1992] EWCA Civ 18 at [31], it does not matter how strong the persuasion was – so long as it does not overbear the independence of the individual's decision. See [32] also for a succinct discussion of the aspects of the effects of outside influences.
40. *Rogers v Whitaker* [1992] HCA 58 per Mason CJ, Brennan, Dawn, Toohey and McHugh JJ at [14] to [15].
41. Above, n3, at [33].
42. In *Re T* [1992] EWCA Civ 18, there were several significant concerns that the patient's generalised refusal was not a settled continuing intention to refuse a blood transfusion in all circumstances. Their Lords considered that the patient's capacity had been compromised, and considered that there was no valid refusal of consent. Notably, the scope of her refusal was limited by her erroneous belief that effective alternative treatments were available.
43. In *Sidaway v The Governors of Bethlem Royal Hospital* [1985] UKHL 1 at 28, Lord Templeman helpfully discusses the balance that doctors (and by this author's expansion, health professionals) seek to attain: "the doctor must decide in light of his training and experience and in light of his knowledge of the patient what should be said. At the same time the doctor is not entitled to make the final decision with regard to treatment which may have disadvantages or dangers. Where the patient's health and future are at stake, the patient must make the final decision."
44. Above, n2, at [30].
45. *Secretary of Department of Health and Community Services v B* [1992] HCA 15; *Secretary, Department of Health and Community Services v JWB and SMB* (1992) 175 CLR 218 at 233; *Rogers v Whitaker* [1992] HCA 58; all cited with approval in *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229 at [25].
46. *Sidaway v The Governors of Bethlem Royal Hospital* [1985] UKHL 1 at 12.
47. Above, n1, at [2].
48. Id at [54].
49. Above, n6, at [19]. ❑