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WITHDRAWING TREATMENT AT THE DIRECT OR INDIRECT REQUEST OF PATIENTS OR IN THEIR BEST INTERESTS: HNEAHS v A; BRIGHTWATER CG V ROSSITER; AND AUSTRALIAN CAPITAL TERRITORY v JT

In Hunter and New England Area Health Service v A [2009] NSWSC 761; Brightwater Care Group (Inc) v Rossiter [2009] WASC 229; and Australian Capital Territory v JT [2009] ACTSC 105 Australian courts have recently considered the circumstances in which technically futile treatment may be withdrawn from patients at their direct or indirect request or purportedly in their best interests. The cases provide many valuable lessons about how norms of ethics, law and international human rights shape the regulatory framework of this area of health care in Australia.

INTRODUCTION

The New South Wales Supreme Court in *Hunter and New England Area Health Service v A* [2009] NSWSC 761 (*HNEAHS v A*), the Western Australian Supreme Court in *Brightwater Care Group (Inc) v Rossiter* [2009] WASC 229 and the Australian Capital Territory Supreme Court in *Australian Capital Territory v JT* [2009] ACTSC 105 have recently considered the circumstances in which technically futile care may be withdrawn from patients either at their direct or indirect request or in their best interests.

THE FACTS OF THREE CASES

The patient in *Hunter and New England Area Health Service v A* [2009] NSWSC 761 (Mr A) was a disabled adult male Jehovah's Witness who, on 1 July 2009, was admitted to the emergency department of a hospital run by the Hunter and New England Area Health Service (HNEAHS). He was suffering from septic shock and respiratory failure and showing a limited level of consciousness. He was transferred to the intensive care unit the following day.

On 19 August 2008, Mr A had completed two documents described as "Worksheet 1" and "Worksheet 2", indicating his attitudes to various forms of medical treatment. Worksheet 2 concerned blood-based medical procedures. Dialysis was among the particular procedures he explicitly refused.

On 5 July 2009, Mr A was attended by a solicitor and a guardianship order was prepared. Mr A executed an instrument in writing appointing two people, Mr T and Mr L, to be his guardians jointly and severally. The appointment was expressed to be enduring (see s 6D of the *Guardianship Act 1987* (NSW)). By that appointment, Mr A authorised each of his enduring guardians, among other things, to decide what health care he should receive and to consent to the carrying out on him of medical or dental treatment.

Although all appropriate treatment had been given to Mr A, his condition deteriorated and he developed renal failure. By 14 July 2009, Mr A was being kept alive by mechanical ventilation and kidney dialysis.

On the same day, HNEAHS became aware of the previously prepared worksheets. HNEAHS subsequently commenced proceedings on 15 July 2009 seeking declarations that these documents were a valid "Advance Care Directive" (ACD) given by Mr A, and that it would be justified in complying with his wishes as expressed by that ACD.

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McDougall J held (at [54]-[57]):

> Worksheet 2 represents a considered decision made by Mr A, and that when Mr A made that decision (and, to the extent that it may be relevant, when he was admitted to hospital), Mr A was in law capable of making the decision to refuse dialysis. I do not know whether the decision to refuse dialysis was based on some religious principle, although there is a basis in the evidence for inferring that it was. But, regardless, it is a considered decision made by a person of legal capacity … I consider that Worksheet 2 in general, and the advance refusal of dialysis in particular, represent Mr A's prospective exercise of his right of self-determination: his right to decide what should be done to his own body. There is nothing in the evidence to suggest that his expression of intent was vitiated in any way. On the contrary, it seems to me to be clear that it was his own voluntary decision. Thus, in my view, the intention expressed in Worksheet 2 was one to which the hospital was required to give effect. To put the matter negatively: I think that Worksheet 2 meant that the hospital could not be taken to have been authorised, by the emergency principle or otherwise, to administer dialysis to Mr A.

In *Brightwater CG v Rossiter* the patient was a quadriplegic in a Western Australian health care facility. He was enduring, on his own estimation, a quality of life that was not reasonably acceptable. The patient testified as follows:

> I am unable to undertake any basic human functions, including, but not limited to: I am unable to talk without a tracheostomy; I am unable to clear the phlegm from my throat to enable me to continue to speak through the tracheostomy; I am unable to speak for any reasonable period of time without my voice tiring and becoming weak; I am unable to walk or move my body at all, apart from involuntary spasmodic movements; I am unable to blow my nose; I am unable to wipe the tears from my eyes. Nursing staff are required to wipe the stools from my bottom. I am unable to brush my teeth. I have been told that there is no hope of rehabilitation or my medical condition improving in any way whatsoever … I have raised my wishes to cease the supply of nutrients to my body with my doctor, Dr Richard Benstead … I endure the following inconveniences on a daily basis as a result of my physical condition: a suppository is inserted every three days …the opening of my bowels that the suppositories induce can be a slow process and a painful process, sometimes taking eight hours … I require a catheter or uridome by way of a condom placed over my penis to pass urine. The urine is collected in a bag attached to my hospital bed. The uridome frequently slips off, soiling both me and the bed linen. This requires frequent changing of the bed linen. Nursing staff must roll me from side to side every six hours or so to prevent bedsores.[1]

After reviewing the position at common law and the relevant Western Australian statutory provisions, Martin CJ made two declarations on 14 August 2009. The first such declaration was:

> If after Mr Rossiter has been given advice by an appropriately qualified medical practitioner as to the consequences which would flow from the cessation of the administration of nutrition and hydration, … Mr Rossiter requests that Brightwater cease administering such nutrition and hydration, then Brightwater may not lawfully continue administering nutrition and hydration unless Mr Rossiter revokes that direction, and Brightwater would not be criminally responsible for any consequences to the life or health of Mr Rossiter caused by ceasing to administer such nutrition and hydration to him.

In *Australian Capital Territory v JT* [2009] ACTSC 105 the Australian Capital Territory Government made an application to the court that it was lawful for medical practitioners employed by it to withhold distressing force-feeding medical treatment via a naso-gastric tube from a 69-year-old man (JT) suffering from paranoid schizophrenia characterised, since the death of Pope John Paul II on 2 April 2005, by religious obsessions that demanded he fast himself to the point of starvation.

JT had resided for 12 years in an Australian Capital Territory nursing home, had no family involved in his care and since April 2005 had been subject to 10 psychiatric treatment orders and nine guardianship orders. The ACT is serviced by two acute tertiary hospitals: a public hospital (The Canberra Hospital (TCH)) and a public-private hospital operated by a Catholic order, the Little Company of Mary (the Calvary Hospital (Calvary)). In 2005 and 2006 JT had been admitted to TCH for re-feeding requiring the use of restraint, but no ward was willing to accept his admission and senior Emergency Department staff felt increasing reservations about restraining him for rehydration. In February 2009, JT was admitted to Calvary and force fed.

[1] *Brightwater Care Group (Inc) v Rossiter* (2406 of 2009); *Rossiter v Brightwater Care Group (Inc)* [2009] WASC 229.

The *Guardianship and Property Act 1991* (ACT), s 7, confers powers on the Public Advocate to consent to medical procedures for incompetent patients, but does not permit such consent to the use of restraint or to the withdrawing and withholding of treatment. The *Mental Health (Treatment and Care) Act 1994* (ACT) gives authority for psychiatric treatment orders, including treatment that is involuntary, but does not accord express authority for the use of force in the provision of medical treatment.

The guardianship orders in place for JT in 2005 and 2006 were made by the Australian Capital Territory Guardianship and Management of Property Tribunal operating within the ACT Magistrates Court and specifically provided the Public Advocate with the power to consent to the use of necessary physical restraint. By February 2009, however, the tribunal had been transferred from the Magistrates Court to the newly created ACT Civil and Administrative Tribunal (the ACAT). The guardianship order in place at the time of JT's August 2009 admission did not include the power to restrain and the tribunal was reported as being disinclined to consent to restraint. This may have been due to the inferior jurisdiction of a tribunal in comparison to the Magistrates Court.

During JT's admission to Calvary in February 2009, he was forceably re-fed by nasogastric tube and developed serous re-feeding syndrome on two occasions. At this time the treating psychiatrist recommended in case notes that a "palliative approach be taken the next time he stops because the force required to feed him is so inhumane". Anita Phillips, the Public Advocate, stated on affidavit that "on numerous more lucid moments" JT "has clearly stated that when he is fasting, he does not want to be forced to eat or receive any interventive treatment". The TCH ethics committee supported the provision of palliative care at its meeting on 22 July 2009.

On Friday 14 August 2009, JT was admitted to TCH with chronic under-nutrition resulting from fasting. He had kidney failure due to dehydration which was redressed through intravenous fluid therapy via a cannula in the foot. The guardianship order in place at this time did not provide for the use of restraint. A decision was made by the treating doctors at TCH not to insert a nasogastric tube through the use of restraint. By 24 August 2009, the Public Advocate, the TCH clinical ethics committee, the treating psychiatrist and specialist involved were all of the view that it was not in JT's best interests to be force fed on the grounds of the inhumanity of the treatment through restraint required to insert a nasogastric tube and the medical risks associated with the alternative form of re-feeding through percutaneous endoscopic gastrostomy (PEG) and additionally that this had been JT's consistently stated preference when lucid. In deciding to seek declaratory relief from the Australian Capital Territory Supreme Court, however, ACT Health quite appropriately appear to have assessed that the risk of criminal charges made it imperative to seek legal "coverage" of any resultant withdrawal or withholding of treatment decision.

Higgins CJ (at [29]) distinguished *Brightwater CG v Rossiter* on the basis that unlike the latter case, the patient before him "lacks both understanding of the proposed conduct and the capacity to give informed consent to it". Higgins CJ declined to make an order that it would be lawful to withhold medical treatment (nasogastric feeding) which was readily available and which might, at least in the short to medium term, avert his otherwise imminent death (at [66]).

THE COMMON LAW RIGHT TO REFUSE MEDICAL TREATMENT

The judgments in all three cases began from the basic proposition that the common law allows a person of recognised capacity to refuse medical treatment, even if that may cause her or his death. In *Schloendorff v Society of New York Hospital* 211 NY 125 at 129 (1914) Cardozo J stated that "[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body". King CJ in *F v R* (1983) 33 SASR 189 at 193 supported "the paramount consideration that a person is entitled to make his own decisions about his life". This statement was cited with approval by Mason CJ, Brennan, Dawson, Toohey and McHugh JJ in *Rogers v Whitaker* (1992) 175 CLR 479 at 487.

The court in *Malette v Shulman* (1990) 67 DLR (4th) 321 at 328 held that

> [a] competent adult is generally entitled to reject a specific treatment or all treatment, or to 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.

The possibility of conflict between this foundational common law right and the human right to life was recognised by Lord Donaldson of Lymington MR in *Re T* [1993] Fam 95 at 112. His Lordship said if there were doubt as to the individual's expression of preference, "that doubt falls to be resolved in favour of the preservation of life". According to Butler-Sloss LJ (at 116), "A decision to refuse medical treatment by a patient capable of making the decision does not have to be sensible, rational or well considered".

In *HNEAHS v A* (at [17]) McDougall J approved of comments in *Airedale NHS Trust v Bland* [1993] AC 789 at 859 by Lord Keith of Kinkel that the state's interest is not absolute, and does not compel treatment of a patient contrary to the patient's express wishes. McDougall J also approved Lord Goff's statement (at 864):

> [I]t 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 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 … [t]o this extent, the principle of the sanctity of human life must yield to the principle of self-determination.

In *Australian Capital Territory v JT* [2009] ACTSC 105 at [26] Higgins CJ specifically supported statements by the court in *Brightwater CG v Rossiter* that a patient of sound mind was competent to refuse nutrition though it would lead to his death and those otherwise under a duty to provide nutrition and treatment would not breach the criminal law by respecting the patient's wishes. However, according to Higgins CJ (at [29]), the patient in this case was not at any time competent to make such a decision, unlike the patient in *Brightwater CG v Rossiter*.

In *HNEAHS v A* McDougall J held that the test of capacity rests on whether the patient in question comprehended the nature, purpose and ramifications of refusing the treatment at the time he or she made that decision.[2] While capacity is presumed for adults, it can be rebutted if impairment or disturbance of mental functions renders the patient incapable of making a decision (at [25]-[27]).[3] His Honour agreed (at [27]-[28]) that a refusal of medical treatment will be vitiated if it is based on incorrect information or an incorrect assumption or the absence of, or failure to provide, 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.

Advance directives and the common law in Australia

Currently, all jurisdictions except New South Wales and Tasmania have enacted legislation allowing patients over the age of 18 the right to make anticipatory or advance health care decisions (an ACD).[4] In the absence of legislation on advance directives, the New South Wales Supreme Court in *HNEAHS v A* approached this application with a focus upon common law principles of the right to refuse treatment.

In *HNEAHS v A* McDougall J stated that the common law recognises two relevant but potentially conflicting interests regarding ACDs:

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[2] *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112; *Re C (Adult: Refusal of Medical Treatment)* [1994] 1 WLR 290; *Re F (Sterilisation: Mental Patient)* [1989] 2 Fam 376.

[3] *Re MB* [1997] 2 FCR 514 (Butler-Sloss LJ).

[4] *Power of Attorney Act 1998* (Qld); *Consent to Medical Treatment and Palliative Care Act 1995* (SA); *Medical Treatment Act 1988* (Vic); *Guardianship and Administration Act 1990* (WA); *Medical Treatment (Health Directions) Act 2006* (ACT); *Natural Death Act 1988* (NT).

- a competent adult's right of autonomy or self-determination: the right to control her or his own body; and
- the interest of the state in protecting and preserving the lives and health of its citizens.

McDougall J refused to approach the issue in the abstract. In *Re T* [1993] Fam 95 an ACD was made by a patient refusing blood products during a caesarean section. The decision was invalidated when it was found that the mother (a Jehovah's Witness) had exerted pressure upon the patient prior to incapacitation. In the case of *NHS Trust v T* [2004] EWHC 1279 (Fam), the 37-year-old female patient made an advance directive forbidding blood products. She was found to be delusionary by way of a borderline personality disorder, and Charles J overrode her ACD.

Courts in such situations are required to examine the strength of will of the patient and the relationship between the patient and persuader to determine undue influence.[5] Any ACD must be intended to apply to the circumstances that have arisen.[6] This is generally determined by interpreting the patient's language and the meaning of particular words and phrases employed, as well as changes in that patient's opinion in the intervening period between making the ACD and the incapacitation and the format of the ACD (whether in writing or orally presented). In the case before him McDougall J, however, pointed out that an over-careful scrutiny of the material may well have the effect of undermining or even negating the exercise of that right (at [36]).

McDougall J held (at [29]) that the principle of necessity cannot be relied upon to justify a particular form of medical treatment where the patient has given an advance care directive specifying that he or she does not wish to be so treated, and where there is no reasonable basis for doubting the validity and applicability of that directive.

PSYCHOTIC DENIAL OF TREATMENT AND NORMALISATION OF DISABILITY

Australian Capital Territory v JT [2009] ACTSC 105 was an unusual case because, although Higgins CJ never expressly framed it as such, it appeared that the psychotically religious man who periodically fasted to starvation had lucid intervals involving reasonable levels of capacity in relation to certain areas of his life. He noted, eg, that "there have been remissions in his obsession" (at [4]). After one involuntary hospital admission and force-feeding he did subsequently for a time eat satisfactorily and gain weight (at [8]). Higgins CJ criticised as "outrageous" a paraphrased determination of the Hospital Clinical Ethics Committee that the patient's wish to starve (presumably when made during a lucid interval) should be respected (at [17]). Yet the crucial issue of whether the patient did have lucid intervals between his psychotic episodes was never directly addressed by Higgins CJ.

It is quite correct that psychotic denial of treatment does not render it futile, particularly if the psychosis is treatable and periodically goes into remission. Higgins CJ undertook a detailed analysis of the Australasian law on futile treatment. He rightly distinguished *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235 in which a court similarly bound as was the Australian Capital Territory Supreme Court to apply the human right to life and the prohibition on cruel or degrading treatment, found that futile treatment could be withdrawn from a patient in a persistent vegetative state. Similarly distinguished were *Airedale NHS Trust v Bland* [1993] AC 789 and *Re G* [1997] 2 NZLR 201. He agreed with Howie J in *Messiha v South East Health* [2004] NSWSC 1061 that futility of treatment could only be determined by consideration of the best interests of the patient and not by reference to the convenience of medical carers or their institutions. Other Australian cases on futility of treatment were also appropriately distinguished.[7]

Yet, the real issue in *Australian Capital Territory v JT* was not futility of treatment but whether the patient had lucid intervals between his psychotic starvation episodes. As Cyeke points out:

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[5] Stewart C and Lynch A, "Undue Influence, Consent and Medical Treatment" (2003) 96 *Journal of the Royal Society of Medicine* 598.

[6] Biegler P, Stewart C, Savulescu J and Skene L, "Determining the Validity of Advance Directives" (2000) 172 MJA 545.

[7] *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549; *Krommydas v Sydney West Area Health Service* [2006] NSWSC 901; *Re BWV; Ex parte Gardner* (2003) 7 VR 487.

> [T]he normalisation principle … promotes the ideal that disabled people should as far as practicable be treated as ordinary individuals. That is their rights to eg medical treatment … should be the same as for non disabled people.[8]

The philosophy of normalisation, which has become a central policy component of the deinstitutionalisation and community living movements for the disabled, was underpinned by a human rights rhetoric – the right to ordinary patterns of life, including participation and social inclusiveness, as well as self-determination. This has included a policy emphasis, with a strong human rights underpinning, in framing disability services and entitlements away from the professional determination of individual needs and towards choice and empowerment for persons with intellectual disability and their families.[9] For example, in 2006 the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) was adopted as a watershed agreement under international law for the rights of persons with disabilities to promote freedom of choice and autonomy, non-discrimination, full participation and inclusiveness in society, respect for the differences evident in persons with disabilities, equality of opportunity, accessibility to core social goods and services and the identification and removal of societal and legal barriers to self-development and enjoyment by people living with disabilities.[10]

The importance of this background to *Australian Capital Territory v JT* is that it may indicate Higgins CJ insufficiently took into account the wishes of the disabled JT during his lucid intervals and in doing so infringed his human rights, as required by the *Human Rights Act 2004* (ACT). Establishing normalisation of the human rights of a disabled person by allowing the person to die at a time and in a manner of her or his choosing may be a hard case. But let's assume JT did have lucid intervals (the crucial and apparently judicially unexplored fact). If so and during such intervals, while competent, the patient decided that, however irrational it might appear to others, God would save him from starvation, that belief should, according to the law previously discussed, have been respected by the court.

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Disclosure: Associate Professor Faunce has served on the Canberra Hospital Clinical Ethics Committee, the decision of which was criticised by Higgins CJ in Australian Capital Territory v JT, but was not involved in the committee's decision in that particular case. The views expressed do not represent those of the NH&MRC and Hilary Russell has contributed to this column in a personal capacity.

[8] Creyke R, *Who can Decide? Legal Decision-making for Others* (AGPS, c 1995) p xxxii.

[9] Herr SS, Gostin LO and Koh HH (eds), *The Human Rights of Persons with Intellectual Disabilities* (Oxford University Press, New York, 2003).

[10] Ward T and Syewart C, "Putting Human Rights into Practice with People with an Intellectual Disability" (2008) 20 *Journal of Developmental and Physical Disabilities* 297, http://www.springerlink.com/content/h4000j8078h8786m/fulltext.pdf viewed 12 November 2009.