

TITLE

No Judge Required:

M (by her litigation friend, Mrs B) v A Hospital; M (Withdrawal of Treatment: Need for Proceedings)

(2017) EWCOP 19

RUNNING HEAD

No Judge Required

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DECLARATIONS

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NO JUDGE REQUIRED:

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SUMMARY

The two titles of the judgment on which this commentary is based reflect the fact that its scope was wider than resolving the legal matter at issue between two parties. It records the reasons for Jackson J.'s decision on a set of facts, it clarifies whether legal proceedings were necessary and the form that they should take, and it explains why the Court of Protection appointed a patient's mother as her litigation friend. The case arose from a request for a declaration that it would be lawful to withdraw clinically assisted nutrition and hydration from a woman with Huntington's disease who had been in a minimally conscious state for about one year. The application for withdrawal was supported by everyone whose evidence was heard. Jackson J. stated that, in such cases, clinicians would be protected by the Mental Capacity Act 2005, and that court proceedings were therefore unnecessary. He explained that, provided that certain criteria are met, and the circumstances are appropriate, a court may appoint a family member or friend – rather than the Official Solicitor – to act as a litigation friend. This commentary explores the implications of this judgment in the context of very recent clinical developments.

[198 words]

KEYWORDS

Disorders of consciousness, vegetative state, minimally conscious state, withdrawal of CANH, necessity of legal proceedings, litigation friend

INTRODUCTION

Individuals who have disorders of consciousness (DoCs) are, in most cases, unable to communicate conventionally. It is therefore necessary that decisions about their medical treatment be taken by others, acting – as is required by the Mental Capacity Act 2005 (MCA) – in their best interests. This principle extends to end-of-life decisions, and a number of cases have centred on the lawfulness of withdrawing clinically assisted nutrition and hydration (CANH) in cases where a patient is able to breathe unaided, and so will die from starvation and dehydration. M, the patient in this case, was in a minimally conscious state (MCS), and her family and clinicians agreed that it would be in her best interests to discontinue CANH. Jackson J. ruled on the facts of the case, and clarified the related issues of whether an application to the Court of Protection (CoP) is necessary if the parties are in agreement, what form such applications should take, and whom a court may appoint as a litigation friend. This commentary summarises the facts and decision in the case, outlines the clinical background and legal framework, considers the dichotomy between the law’s approaches to MCS and permanent vegetative state (PVS), reviews the legal consequences of the decision, and concludes by expressing the hope that neuroimaging technology may eventually enable the ‘voice’ of a patient with a DoC to be heard.

THE FACTS

M was diagnosed as suffering from Huntington’s disease, a degenerative neurological condition, in the mid-1980s. By 1994 she was living in hospital, and by 2003 she was dependent on CANH. From around 2007 she was bedridden, although she was sometimes transferred to a wheelchair for short periods. Her family showed her great devotion, and her mother, Mrs B, visited the hospital four times a week.¹ In July 2016, the hospital, supported by M’s family, decided that it was no longer in M’s best interests to continue to administer CANH, and applied to the court for a declaration that

¹ *M (by her litigation friend, Mrs B) v A Hospital* (2017) EWCOP 19 [9]

discontinuation would be lawful. Three doctors – two consultants who had been responsible for M’s care, and one specialist in Huntingdon’s disease – noted that M appeared to be experiencing pain and discomfort: her heart rate dropped when she was given pain relief, and she grimaced when she was moved. Other healthcare professionals – the multi-disciplinary team, the clinical nurse leader, the social worker and the consultant clinical psychologist – also supported the application for withdrawal of CANH. As all interested parties supported the application, they questioned the necessity of the legal proceedings.

THE JUDICIAL DECISIONS

Jackson J. began by setting out the legal framework for determining M’s best interests (this is summarised below): the relevant requirements of the MCA and Baroness Hale’s *dictum* in *James* regarding substituted judgment.² He accepted the evidence of M’s family and the clinicians, observing that they had all placed M ‘at the centre of their concern’.³ Although conscious that ‘there are always more investigations that can be made, questions that can be asked, stones that can be turned’,⁴ Jackson J. held, at a hearing on 22 June, that CANH could be discontinued after a meeting to agree a timetable. M was transferred to palliative care on 24 July, and died, aged 50, on 4 August.

The remainder of the judgment was issued after the hearing, in response to written submissions from the Official Solicitor and all parties. In this addendum, Jackson J. considered whether proceedings were necessary in all cases involving the possible withdrawal of CANH from patients in PVS or MCS.⁵ After summarising the recent consideration that had been given to Practice Direction

² *M (by her litigation friend, Mrs B) v A Hospital* (2017) EWCOP 19 [20]–[24]

³ *M (by her litigation friend, Mrs B) v A Hospital* (2017) EWCOP 19 [26]

⁴ *M (by her litigation friend, Mrs B) v A Hospital* (2017) EWCOP 19 [27]

⁵ *M (by her litigation friend, Mrs B) v A Hospital* (2017) EWCOP 19 [28]–[38]

9E (the PD),⁶ he held that, provided the decision to withdraw CANH were taken in accordance with the relevant guidelines,⁷ the decision would be lawful. The clinicians would therefore have immunity under MCA, section 5, which provides that a person will not incur liability for any non-negligent act ‘in connection with care or treatment’ if he or she reasonably believes that a patient lacks capacity to consent to the act, and that the act is in the patient’s best interests. In M’s case, because of the unanimity of views, CANH could have been lawfully discontinued without reference to the court. Jackson J. also considered the appropriate form for applications for the withdrawal of CANH, ruling that, where the central issue was the patient’s best interests, applications should be brought under MCA, sections 15–17, rather than – as had happened in this case – section 21A. In the final section of his judgment, Jackson J. observed that a litigation friend can be anyone who can fairly and competently conduct the proceedings on the person’s behalf, and who has no interests that are adverse to the person’s.⁸ There was no reason to believe that Mrs B failed to meet these criteria: she had conducted the proceedings competently by instructing specialist lawyers.

COMMENTARY

Clinical Background

Patients in a vegetative state (VS) are unaware of their own existence or environment. The condition is considered to be permanent if it persists for at least six months after anoxia or a metabolic brain

⁶ Practice Direction 9E: Applications Relating to Serious Medical Treatment – effective from 1 July 2015 [online]. Available at <https://www.judiciary.gov.uk/publications/practice-direction-9e-applications-relating-to-serious-medical-treatment-effective-from-1-july-2015/> (accessed 28 November 2017)

⁷ Jackson J. identified these as: the GMC’s *Good Medical Practice* guidance, the BMA’s *Withholding and Withdrawing Life-prolonging Medical Treatment and End of Life Care*, and the Royal College of Physicians’ *Guidance on Prolonged Disorders of Consciousness*.

⁸ Court of Protection Rules 2007/1744, Rule 140

injury, or least 12 months following a traumatic brain injury.⁹ MCS was not identified as a separate condition until 2002, and is diagnosed when a patient exhibits behaviours including following simple instructions, speaking intelligibly, acting purposefully, responding to emotional stimuli, or following objects with their eyes.¹⁰ It is likely that some cases in which patients were described as being in PVS actually involved people in MCS,¹¹ and one study – conducted before MCS was clinically defined – found that 43% of 40 patients had been misdiagnosed as being in PVS, and a further 33% of them slowly emerged from their completely unresponsive state.¹² Adrian Owen, a leading neuroscientist, has recently asserted that 15%–20% of people who are completely unresponsive – and therefore apparently in PVS – are fully conscious.¹³

The Legal Framework

In *Airedale NHS Trust v Bland*¹⁴, the House of Lords held that the withdrawal of CANH was in the best interests of a 19-year-old victim of the Hillsborough disaster who had been in PVS for three-and-a-half years. The MCA codified the ‘best interests’ test from *Bland* as the paramount consideration in all cases involving mentally incapacitated patients, and specified that best interests are to be determined by taking into account all relevant considerations, including the patient’s past and present wishes and feelings, their relevant beliefs, and other factors that they would be likely to consider if able to do so.¹⁵ Lady Hale has explained that the MCA’s ‘best interests’ test includes

⁹ Royal College of Physicians *Guidance on Prolonged Disorders of Consciousness: National Clinical Guidelines* (Royal College of Physicians, London 2013)

¹⁰ JT Giacino *et al.*, ‘The minimally conscious state: definitions and diagnostic criteria’ (2002) *Neurology* 58 (3) 349–353

¹¹ A Mullock, ‘Deciding the fate of a minimally conscious patient: an unsatisfactory balancing act?’ (2012) *Medical Law Review* 20 (3) 460–469

¹² K Andrews *et al.*, ‘Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit’ (1996) *BMJ* 313 13–16

¹³ A Owen, ‘Into the grey zone: how science found a way to speak to coma patients’ (2017) *The Guardian* 5 September: 25–27

¹⁴ *Airedale NHS Trust v Bland* [1993] AC 789

¹⁵ Mental Capacity Act 2005, sections 1(5) and 4(6)

decision-makers attempting ‘to put themselves in the place of the individual patient’ and consulting others as to what the patient’s view would be.¹⁶

The first case involving the withdrawal of CANH from a patient identified as being in MCS was *W. v M*,¹⁷ in which Baker J ruled that the importance of preserving life was the decisive factor, and so CANH must continue, despite the unchallenged evidence of three members of the patient’s family that she would not have wished to be kept alive in such circumstances. In *M v N*,¹⁸ Hayden J. determined that ‘respect for Mrs N’s dignity and human freedom’ should prevail over the principle of preserving life, and ruled that CANH could be discontinued.

The European Convention on Human Rights (ECHR), Articles 2 and 3 (the right to life, and the right to protection from torture or inhuman or degrading treatment) apply in such cases, since withdrawal of CANH results in death, and its inappropriate administration can prolong a patient’s suffering. The legal position before *M* was that the CoP should hear all applications for cases involving the withdrawal of CANH from people in PVS or MCS.¹⁹ The rebuttable presumptions underlying such cases are that it is lawful to withdraw CANH from a patient in PVS,²⁰ but that it is normally in the best interests of a patient in MCS to remain alive.²¹

An Inappropriate Dichotomy

It is dangerous to assume that diagnoses of PVS or MCS are invariably correct – as noted above, there are significant concerns about accuracy – or immutable. It is very rare for a patient to emerge

¹⁶ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 [35]

¹⁷ *W (by her litigation friend, B) v M (by her litigation friend, the Official Solicitor)* [2011] EWHC 2443

¹⁸ *M v N (by her litigation friend, the Official Solicitor) and others* [2015] EWCOP 76 (Fam)

¹⁹ Court of Protection Practice Direction 9E, *Applications relating to Serious Medical Treatment – effective from 1 July 2015*

²⁰ *A Hospital v SW* [2007] Med LR 273 [8], quoted with approval by Baker J in *M v N (by her litigation friend, the Official Solicitor) and others* [2015] EWCOP 76 (Fam) [47]

²¹ *W (by her litigation friend, B) v M (by her litigation friend, the Official Solicitor)* [2011] EWHC 2443 [7]

from PVS after more than two years, or from MCS after more than five years.²² Since the full judgment in *M* on 20 September 2017, however, the press have reported two instances where individuals diagnosed as being in PVS for longer periods have demonstrated responsive behaviour indicative of MCS. In the first case, Margaret Worthen had been diagnosed as being in PVS for six years. In 2012, she became able to express herself by blinking and moving her left eye. Magnetic resonance imaging showed that, over two years, her brain had ‘essentially rewired’, developing more inter-hemispheric structural and functional connections in the area of her brain responsible for speech.²³ The other case involved a 35-year-old man who had been in PVS for 15 years following a car accident,²⁴ and had been completely unresponsive until an implant to enable electrical stimulation of the vagus nerve was inserted into his neck. After a month of stimulation, he showed improvements in his levels of awareness and arousal, was able to track objects with his eyes, and could make some voluntary movements. As well as these behavioural changes, two forms of neuroimaging showed significant increases in brain activity.²⁵ It is therefore inappropriate for the law to differentiate so starkly between cases where a patient’s diagnosis is PVS and those where it is MCS: the former can no longer be regarded as a state from which a patient will inevitably not recover.

The Legal Consequences of M

The judgment in *M* changes neither the legal framework nor its effect in cases where it is held to be in the best interests of a patient in MCS to discontinue CANH. Subject to the *caveat* that the CoP’s judgments constitute only persuasive precedents, the judgment in *M* has three consequences: it

²² Royal College of Physicians’ *Guidance on Prolonged Disorders of Consciousness: National Clinical Guidelines* (Royal College of Physicians, London 2013)

²³ JJ Fins, ‘Brain Injury and the Civil Right We Don’t Think About’ (2017) *The New York Times* 24 August

²⁴ H Devlin, ‘Nerve implant raises alertness of man in vegetative state’ (2017) *The Guardian* 26 September

²⁵ M Corazzol, G Lio, A Lefevre *et. al.*, ‘Restoring consciousness with vagus nerve stimulation’ (2017) 27 (18) *Current Biology* R994–R996. Available at <http://dx.doi.org/10.1016/j.cub.2017.07.060> accessed 27 September 2017.

removes the need for legal proceedings in undisputed cases, changes the appropriate form of applications in disputed cases, and confirms that the litigation friend of patients with DoCs need not be the Official Solicitor. These issues are considered below.

The need for legal proceedings

The PD specifies that cases involving the withdrawal of CANH from patients with DoCs should be brought to court,²⁶ but Jackson J noted that during 2017 the CoP Rules Committee had recommended the removal of the PD, and a group had been created to specify which cases should be litigated. Also in 2017, the Court of Appeal had stated that doctors administering any undisputed medical treatment that was in the patient's best interests would have immunity under MCA, section 5, although disputed cases involving the withdrawal of CANH from incapacitated people should still be referred to the CoP.²⁷ In addition to considering the parties' written submissions, Jackson J. invited observations from the Official Solicitor, who 'trenchantly' asserted that the CoP should determine every case of proposed withdrawal of CANH where there was not a valid advance directive, in order to ensure compliance with ECHR Article 2, which protects the right to life.²⁸

Jackson J. pointed out that decisions involving the withdrawal of life-support were overwhelmingly taken by clinicians and families without judicial intervention, and opined that it was anomalous to require litigation only if the patient had a DoC. Such cases were not so different from other end-of-life decisions that it was necessary and proportionate that they required legal proceedings: 'the right to life belongs to everyone ... many of us will at some time in our lives come to be in a precarious

²⁶ Practice Direction 9E: Applications Relating to Serious Medical Treatment – effective from 1 July 2015 [online], para. 5(a). Available at <https://www.judiciary.gov.uk/publications/practice-direction-9e-applications-relating-to-serious-medical-treatment-effective-from-1-july-2015/> (accessed 28 November 2017)

²⁷ These *dicta* were from King LJ in *Director of Legal Aid Casework and Others v Briggs* [2017] EWCA Civ 1169, [108], quoted in *M (by her litigation friend, Mrs B) v A Hospital* (2017) EWCOP 19 [29]

²⁸ *M (by her litigation friend, Mrs B) v A Hospital* (2017) EWCOP 19 [30]

state'.²⁹ It is difficult to fault the logic of this part of the judgment. Some patients who are on mechanical ventilators or other types of somatic life-support are heavily sedated for a variety of reasons,³⁰ and so cannot communicate their wishes. If doctors and family members agree that it is not in a patient's best interests that life-prolonging treatment should continue, palliative care ensures that these patients die peacefully. Similarly, the alleviation of M's suffering was expressly considered: nutrition and hydration were withdrawn together, and palliative care was administered to minimise her discomfort.

Jackson J. also noted the deterrent effect of proceedings: M had received CANH for a year after anyone believed it was in her best interests, because it could not be withdrawn until after the hearing. Again, his logic is difficult to fault: if the patient's best interests have been agreed upon, it is absurd that meeting those interests should be delayed – and a patient's suffering extended – because of a procedural legal requirement.

The form of future applications

The parties' costs were around £30,000, which Jackson J. described as 'a fraction' of what they would have been in a contested application.³¹ In *M*, as in *Briggs*,³² the application was brought under MCA, section 21A, which covers cases involving patients' deprivation of liberty under Schedule A1. Jackson J. recognised that the guarantee of non-means-tested legal aid in cases brought under section 21A³³ resolved an issue of 'serious practical concern' for families in cases involving serious

²⁹ *M (by her litigation friend, Mrs B) v A Hospital* (2017) EWCOP 19 [37]

³⁰ K Rowe and S Fletcher, 'Sedation in the intensive care unit' *Continuing Education in Anaesthesia Critical Care & Pain* (2008) 8 (2): 50–55

³¹ *M (by her litigation friend, Mrs B) v A Hospital* (2017) EWCOP 19 [19]

³² *Director of Legal Aid Casework and Others v Briggs* [2017] EWCA Civ 1169 – see N. 27 *supra*

³³ Civil Legal Aid (Financial Resources and Payment for Services) Regulations 2013/480, Reg. 5(1)(g)

medical treatment, but the Court of Appeal had recently ‘swept away two fictions’³⁴: the provision of CANH to a person in PVS or MCS could not be described as a deprivation of liberty, and it was inappropriate to distort the legal framework by substituting section 21A for sections 15–17 where the point at issue was – as in this case – the patient’s best interests.³⁵ Jackson J. observed that the automatic provision of legal aid in deprivation of liberty cases ensures that the state honours its obligation to protect individuals’ rights under ECHR Article 5, and stated that similar support was even more essential where the right to life under Article 2 was at stake.

Similar considerations presumably apply to Article 3, which protects the right to freedom from torture and inhuman or degrading treatment; this is one of only three Articles that set out absolute rights. Prolonging the life of a patient in MCS, when no one considers this to be in their best interests, could be breaching Article 3 by subjecting that person to a form of mental torture by prolonging physical pain – as the European Court of Human Rights has observed:

The suffering which flows from naturally occurring illness, physical or mental, may be covered by Article 3, where it is, or risks being, exacerbated by treatment, whether flowing from conditions of detention, expulsion or other measures, for which the authorities can be held responsible ...³⁶

Despite the logic and power of these considerations, it seems unlikely that legal aid will be extended to cover any additional types of case. An undesired effect of Jackson J.’s ruling may therefore be that people will not be able to afford to ask the CoP to hear their views on whether the CANH of a family

³⁴ *M (by her litigation friend, Mrs B) v A Hospital* (2017) EWCOP 19 [39]. The cases referred to were *Ferreira v HM Senior Coroner for Inner South London* [2017] EWCA Civ 31 and *Director of Legal Aid Casework and Others v Briggs* [2017] EWCA Civ 1169

³⁵ Sections 15–17 provide that a court may make decisions and declarations about the welfare of, and appoint deputies to make decisions of behalf of, people who lack capacity, and cases brought under these sections do not attract non-means-tested legal aid.

³⁶ *N v United Kingdom* (App. no. 26565/05) ECHR 2008-III 227 [29]

member should be discontinued, meaning that the views of doctors may by default prevail in cases where there could be valid, best-interests-based, arguments against them.

The litigation friend

Jackson J.'s confidence that Mrs B was a competent litigation friend is not disputed, but it is arguable whether close relatives of someone with a DoC can ever suppress their own feelings sufficiently to determine the patient's best interests with complete impartiality. Watching a loved one suffer is an agonising experience, and few people have thought seriously about whether, if they were what Mrs B described as 'a body on a bed',³⁷ they would prefer to have their probably hopeless situation ended, or be given the continued opportunity to look out of a window or hear their grandchildren's voices, despite the numerous indignities. While there is no doubting the sincerity of M's family's expressed views that it 'seems cruel' to prolong her life artificially,³⁸ that the CANH was 'simply causing M to suffer',³⁹ and that 'it would have really distressed her if she knew that she would be left living in this way'⁴⁰, it is difficult to be certain that the speakers had completely disentangled the tragedies of M's and their own plights.

Although any submissions from the Official Solicitor are unaffected by subjectivity, they are not a panacea, because it is impossible to know whether the person with the DoC would prefer someone with no other involvement to be engaged to argue on their behalf, or to spare their family the additional stress and expense that this may involve. Nonetheless, the involvement of the Official Solicitor has the merit of ensuring, as far as is possible in a formulaic legal process, that the best interests of any patient in a contentious case are represented by a wholly disinterested advocate. This avoids any possible conflict of interest on the part of relatives, who may find it impossible to

³⁷ *M (by her litigation friend, Mrs B) v A Hospital* (2017) EWCOP 19 [9]

³⁸ *M (by her litigation friend, Mrs B) v A Hospital* (2017) EWCOP 19 [10] – Mrs B said this

³⁹ *M (by her litigation friend, Mrs B) v A Hospital* (2017) EWCOP 19 [11] – M's husband said this

⁴⁰ *M (by her litigation friend, Mrs B) v A Hospital* (2017) EWCOP 19 [12] – M's adult daughter said this

separate the distress that they feel on behalf of their loved one from the personal distress that they feel at witnessing such suffering.

The Hope: Enabling the Patient's Own Voice to be Heard

The near-impossibility of anyone being able to state a patient's views with complete confidence in such crucial circumstances underlines the urgent need for all possible steps to be taken to communicate with patients who have DoCs. Ascertaining patients' views would remove from families the burden of attempting to represent a loved one's view on the continuation of their life, and would remove the need for litigation. Although many people in MCS cannot communicate by conventional means, a number of neuroimaging techniques have been used to 'read' their thoughts. The most dramatic reported results have been achieved by functional magnetic resonance imaging (fMRI), which has been pioneered by Owen and colleagues. fMRI shows which areas of the brain are most active at any time. If someone is asked to envisage playing tennis, the supplementary motor area becomes active; envisaging walking round one's home activates the parahippocampal gyrus.⁴¹ If patients with DoCs can repeatedly demonstrate these responses, they are asked six questions with known answers – such as: 'Is your father's name Alexander?' – and told to imagine playing tennis if the answer is 'no', or walking round their homes if the answer is 'yes'. If they can do this reliably, it is possible to have conversations with them, and this technique was used by Owen to ascertain significant information about Scott Routley, who was believed to have been in PVS for 12 years.⁴² Routley knew what year it was, where he was, who his primary carer was, and – crucially – he was able to confirm that he was not in pain.

⁴¹ M Monti *et al.*, 'Wilful Modulation of Brain Activity in Disorders of Consciousness' *New England Journal of Medicine* (2010) 362: 579–589

⁴² A Owen, 'Into the grey zone: how science found a way to speak to coma patients' (2017) *The Guardian* 5 September: 25–27

Whenever it becomes clear that a patient has this level of consciousness, the diagnosis changes to MCS, even if they remain unresponsive to normal bedside testing methods. If they are being sustained by CANH, fMRI could enable them to indicate whether they wished this to continue. Provided that the question were asked in different ways, and the answers were consistent, family members and doctors would be able to enjoy the confidence that – irrespective of the outcome – they were complying with the patient’s wishes. This desirable situation can be achieved only if research into portable equipment, and robust and reliable imaging techniques, continues. The eventual outcome may be that the 15–20% of people who are fully conscious,⁴³ despite their being ‘assumed to have no more awareness than a head of broccoli’,⁴⁴ will no longer need anyone to undertake the burden of making a substituted judgment.

For MCS patients who cannot communicate in any reliable way, and whose best interests are agreed upon by all concerned, *M* removes a legal obstacle to a peaceful death; for this reason, and for its pragmatic approach, the judgment is welcome.

(4,163 words, plus Abstract, keywords, footnotes and endnote)

ⁱ This Commentary was accepted before the High Court’s announcement, in *NHS Trust v Mr Y (by his Litigation Friend, the Official Solicitor) and Mrs Y* [2017] EWHC 2866 (QB), that Court of Protection Practice Direction 9E would be revoked on 1 December 2017. Jackson J.’s judgment expresses his awareness of misgivings about the PD, and his decision not to uphold the Official Solicitor’s argument on the need for the CoP to hear all cases involving the withdrawal of CANH from patients in MCS or PVS indicates pragmatic foresight: *M* would not have reached the CoP if the revocation had occurred before 22 June 2017.

⁴³ See A Owen, ‘Into the grey zone: how science found a way to speak to coma patients’ (2017) *The Guardian* 5 September: 25–27 NOTE 11 *supra*

⁴⁴ A Owen, ‘Into the grey zone: how science found a way to speak to coma patients’ (2017) *The Guardian* 5 September: 25–27 page 26