

Live or Let Die?

The Court of Protection's Ground-Breaking Decision in *M. v. N. (by her litigation friend, the Official Solicitor) and others* [2015] EWCOP 76 (Fam.)

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Abstract

This case note examines the first case in which the Court of Protection authorised the withdrawal of life-sustaining nutrition and hydration from a patient in a minimally conscious state. It reflects on the judge's stated view that the label given to the patient's condition is not determinative, examines the significance and interpretation of the 'best interests' test, compares the court's decision with that in a 2011 case with similar facts, and questions the law's differing approaches to patients in the minimally conscious and 'vegetative' states. It concludes with a brief explanation of ways in which clinicians might – now and, subject to the robustness of emerging neuroimaging technology, in the future – be able to ascertain the views of people who cannot communicate in conventional ways, and expresses the hope that future judges will give priority to their patients' wishes, to the extent that these can be ascertained.

I. Introduction

M. v. N. (by her litigation friend, the Official Solicitor) and others is the first Court of Protection case authorising the withdrawal of life-sustaining clinically assisted nutrition and hydration from a patient diagnosed as being in a minimally conscious state (MCS).¹ It represents a significant shift in the courts' approach to artificially prolonging the lives of patients who cannot express their own wishes regarding treatment, and has been widely reported as a 'landmark ruling'.²

Hayden J. set out the methods of clinical assessment used in the case, and carefully considered the meaning of the 'best interests' test under section 1(5) Mental Capacity Act 2005 (MCA). Although stating how thought-provoking he had found Baker J.'s observations in *W. (by her litigation friend, B.) v. M. (by her litigation friend, the Official Solicitor)* – the only precedent case involving a patient

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¹ *M. v. N. (by her litigation friend, the Official Solicitor) and others* [2015] EWCOP 76 (Fam.).

² See, e.g. Nicola Slawson, 'MS sufferer should be allowed to die, says judge in landmark ruling', *The Guardian*, 19 November 2015 (Online) <https://www.theguardian.com/society/2015/nov/19/ms-sufferer-should-be-allowed-to-die-judge-landmark-ruling-multiple-sclerosis>, accessed 20 November 2015.

in MCS – he departed from that decision without expressly distinguishing it.³ He declined to analyse the patient’s best interests using a ‘balance sheet’, and disregarded the name given to her prolonged disorder of consciousness in favour of a pragmatic assessment of her condition.⁴

This commentary notes clinical and other similarities between *M. v. N.* and *W. v. M.*, and ponders their different outcomes. It outlines a way in which some patients in MCS may be enabled to communicate – now and, subject to the robustness of emerging neuroimaging technology, in the future – and reflects on a perverse aspect of the current law. It concludes with the hope that future judges, like Hayden J., will prioritise individual patients’ wishes, so far as they can be ascertained.

2. Legal and Clinical Background

People in MCS and vegetative state (VS) cannot communicate by conventional means.⁵ They are regarded as lacking capacity for the purposes of the MCA, so others’ decisions concerning their treatment must be made in their best interests.⁶ This involves considering all relevant circumstances, including their past and present wishes and feelings, their relevant beliefs and values, and other factors that they would be likely to consider if able to do so.⁷ The leading case involving this test is *Aintree University Hospitals NHS Foundation Trust v. James*, where Baroness Hale confirmed (at paragraph 24) that the test of a patient’s best interests included ‘a strong element of substituted judgment’ – this factor, as the Official Solicitor pointed out in *M. v. N.*, ‘ensures that P as a human being remains at the very centre of decision-making’.⁸

³ *W. (by her litigation friend, B.) v. M. (by her litigation friend, the Official Solicitor)* [2011] EWHC 2443.

⁴ The ‘balance sheet’ approach was used by Thorpe L.J. in *Re A. (Male Sterilisation)* [2000] 1 FLR 549, at 560 F–H.

⁵ The term ‘vegetative state’ has been criticised for likening human beings to vegetables. A proposal to re-name the condition ‘unresponsive wakefulness syndrome’ (S. Laureys et al., ‘Unresponsive wakefulness syndrome: a new name for the vegetative state or apallic syndrome’ *BMC Medicine* 8 (2010): 68) was not widely adopted, and the Royal College of Physicians, which publishes the Guidelines on which Hayden J. heavily relied (Royal College of Physicians, *Prolonged disorders of consciousness: National clinical guidelines*. (London: RCP, 2013)) prefers ‘VS’ on the basis that ‘unresponsive wakefulness syndrome’ has not been fully defined.

⁶ MCA s. 1(5).

⁷ *Ibid.* ss 4(2) and 4(6).

⁸ *Aintree University Hospitals NHS Foundation Trust v. James* [2013] UKSC 67. See [2015] EWCOP 76 (Fam.), para. 27(c).

Patients in VS are unresponsive, and have apparent periods of sleep and wakefulness because they open and close their eyes cyclically.⁹ They may involuntarily smile, moan or utter single words, are doubly incontinent and may spontaneously grind their teeth, roll their eyes or shed tears. Crucially, there is no evidence that they are aware of themselves or their surroundings.¹⁰

MCS was first distinguished from VS in 2002. It is regarded as the appropriate diagnosis if a largely unresponsive person can consistently follow simple commands, articulate or indicate positive and negative responses (irrespective of accuracy), speak intelligibly or exhibit purposeful behaviour such as reaching towards an object.¹¹

It is difficult to differentiate between these two prolonged disorders of consciousness, and Hayden J. identified three structured assessment tools that are routinely used in diagnosis.¹² He noted that the Royal College of Physicians' Guidelines ('the Guidelines') stress the importance of the observations of a patient's family and friends.¹³ He observed that the risk of optimism inherent in all subjective observations necessitates their being treated with a measure of caution: loved ones may be 'driven by hope and no doubt wishful thinking', while professionals may be 'driven by a vocational desire to try to make a difference'.¹⁴

The Court of Protection determines all cases involving the proposed withholding or withdrawal of artificial hydration and nutrition (ANH) from people in VS or MCS.¹⁵ The statutory Code of Practice states that: 'All reasonable steps which are in the person's best interests should be taken to prolong their life', acknowledging that it may be lawful to withdraw or withhold life-sustaining treatment if it is 'futile, overly burdensome to the patient or where there is no prospect of recovery'.¹⁶

⁹ Royal College of Physicians, 2013.

¹⁰ C. Schnakers, J. Giacino & S. Laureys, 'Coma: Detecting signs of consciousness in severely brain injured patients recovering from coma', in J.H. Stone & M. Blouin (eds), *International Encyclopedia of Rehabilitation*, (2010) (Online) <http://cirrie.buffalo.edu/encyclopedia/en/article/133/>, accessed 26 November 2015. Royal College of Physicians, *The Vegetative State: Guidance on diagnosis and management* (London: RCP, 2003). Royal College of Physicians, *Prolonged disorders of consciousness: National clinical guidelines*. (London: RCP, 2013).

¹¹ J.T. Giacino et al., 'The minimally conscious state: Definition and diagnostic criteria', *Neurology* 58:3 (2002), 349-353.

¹² [2015] EWCOP 76 (Fam.), para. 21.

¹³ Royal College of Physicians, 2013.

¹⁴ [2015] EWCOP 76 (Fam.), para. 22.

¹⁵ Court of Protection Practice Direction 9E, *Applications relating to Serious Medical Treatment – effective from 1 July 2015*, para. 5(a). Although this Practice Direction was issued after *W. v. M.*, the judgment in that case refers (at para. 78) to 'PD9E paragraph 5' in terms that make it clear that this aspect of the Practice Direction has not been changed by the most recent update.

¹⁶ Department for Constitutional Affairs, *Mental Capacity Act 2005 Code of Practice*. (London: TSO, 2007), para. 5.31.

Consideration of the patient's best interests traditionally involves a 'balance sheet' of factors for and against prolonging life, but it is accepted that people in VS are unaware of their own existence, so treatment may be discontinued.¹⁷ This codifies the decision in *Airedale NHS Trust v. Bland*, in which the House of Lords and Court of Appeal upheld the High Court's ruling that withdrawing ANH would be in the best interests of Tony Bland, who had been in VS for over three-and-a-half years.¹⁸

W. v. M. was described by Hayden J. as the only precedent case involving a patient diagnosed as being in MCS.¹⁹ In 2003, M., then a 52-year-old woman, contracted viral encephalitis that caused extensive, irreparable brain damage, leaving her completely dependent on others, and sustained by ANH. After some time in a coma, she emerged into VS, and in 2007 an application was made for a declaration that it would be lawful to withdraw her ANH. At that time, she was re-assessed as being in MCS, so it was necessary to conduct a thorough assessment of her best interests. Baker J. heard evidence from three members of M.'s family, several of her carers, a specialist occupational therapist and two medical experts.²⁰ The experts differed as to the severity of M.'s condition; Baker J. determined that she was 'at a moderate level on the MCS spectrum', and this factor was highly influential in his analysis of her best interests. He ruled that 'the importance of preserving life is the decisive factor in this case', and ordered that ANH be continued.²¹

3. *M. v. N.*

Mrs N. was diagnosed with multiple sclerosis in 1992, when she was 45. The disease progressed relentlessly, and in April 2015, Mrs N.'s daughter, M., issued Court of Protection proceedings seeking the discontinuation of her mother's ANH. The Official Solicitor acted as Mrs N.'s litigation friend;

¹⁷ This view is apparent in the speeches of Lords Browne-Wilkinson and Mustill in *Airedale NHS Trust v. Bland*: [1993] A.C. 789 at 879 and 896 respectively.

¹⁸ [1993] A.C. 789, [1993] 2 W.L.R. 316.

¹⁹ It has been pointed out that it is likely that some patients in earlier cases had in fact been in MCS, but had not been described as such because their cases occurred before MCS was identified as being a condition distinct from VS – see Alexandra Mullock, 'Deciding the fate of a minimally conscious patient: an unsatisfactory balancing act?', *Medical Law Review* 20:3 (2012), 460-469.

²⁰ M.'s mother, W., initiated the application. By the time of the full hearing, W. was too ill to participate, so M.'s daughter, B., and M.'s long-term partner were the only family members who gave evidence to the court.

²¹ [2011] EWHC 2443, paras 238 and 249.

Bury Clinical Commissioning Group and ‘A care provider’ were the other respondents.²²

Hayden J. heard evidence from Mrs N.’s ex-husband and son, as well as M. He described the family as having given Mrs N. ‘a clear voice in this courtroom’, and he had no difficulty in accepting their view that ‘she would have wished to have discontinued her treatment some considerable time ago’.²³

The three medical experts gave different assessments of Mrs N.’s condition. Following a discussion in court, they had agreed that the SMART structured assessment tool had really established only that Mrs N. could follow objects with her eyes.²⁴ Two of the doctors contended, following the Guidelines, that this precluded VS, and therefore diagnosed Mrs N. as being in MCS; the third considered that she was in VS.²⁵ Hayden J. articulated his dilemma:

*What emerges therefore is agreement between the doctors as to the clinical findings and disagreement as to the correct nomenclature to be applied. Whether Mrs N. is in VS or MCS has important consequences for how I apply the law but it is an arid debate clinically given all now agree on the relevant medical facts.*²⁶

Hayden J. considered that ‘some level of awareness remains’, so Mrs N. was not in VS, and he therefore had to determine where her best interests lay.²⁷ Having heard her family’s evidence, noted that the Official Solicitor had withdrawn his opposition to the application and considered the case law, Hayden J. concluded that ‘respect for Mrs N.’s dignity and human freedom overwhelms further prolongation of life’, and granted the application to discontinue ANH.²⁸

4. Discussion

There are significant clinical parallels between *M. v. N.* and *W. v. M.*. Mrs N. was quadriplegic, unable to communicate normally, doubly incontinent, permanently in a flexed position that rendered her unable to sit in a wheelchair, epileptic, subject to frequent chest infections, and suffering

²² Both these respondents took a neutral stance to the application; counsel for ‘A care provider’ drew the Court’s attention to Art. 8 European Convention on Human Rights ([2015] EWCOP 76 (Fam.), para. 76), but no other submissions from either respondent are recorded.

²³ [2015] EWCOP 76 (Fam.), para. 59.

²⁴ SMART is an acronym for Sensory Modality Assessment and Rehabilitation Technique, which consists of behavioural observation and sensory assessment, conducted over a three-week period. [2015] EWCOP 76 (Fam.), para. 36.

²⁵ [2015] EWCOP 76 (Fam.), paras 37-39.

²⁶ *Ibid.*, para. 44.

²⁷ *Ibid.*, paras 47, 49.

²⁸ *Ibid.*, paras 63, 65-69, 79.

from severe pressure sores.²⁹ M. was immobile, doubly incontinent, had limited control of her head and trunk, and suffered from severe spasticity in her limbs, but could sit in a chair and had no pressure sores.³⁰ Unlike Mrs N., M. occasionally reacted to environmental stimuli, including responding to music.³¹ There was general agreement that M. experienced pain, distress or discomfort; one carer suggested this occurred around 30% of the time.³² Although M. exhibited more characteristics of MCS than did Mrs N., her prospects of significant recovery were similarly remote.³³

Any best interests assessment in such cases must address the conflict between the sanctity of life, which Hayden J. described as ‘an ideological imperative found in (...) all major religions’, and respect for individual autonomy.³⁴ The latter involves determining, so far as possible, the individual’s wishes, and both judges took considerable pains to establish as much as they could about their patients’ personalities. The families gave uncontested evidence that both women had stated that they would not wish to live in circumstances where they were dependent on others: Mrs N. had been heartbroken when her parents suffered from dementia, and had said: ‘If I ever get like that shoot me!’, and M.’s partner confirmed that M. had said more than once that she would never wish to be put into a nursing home, and that she would have been horrified by the lack of dignity inflicted by her illness.³⁵ A clear picture emerges of each woman as an independent and proud individual who was very conscious of her appearance.³⁶

Given these similarities, it is interesting that the cases had different outcomes. Baker J. adopted the conventional approach that the sanctity of life must prevail because he found that there was no evidence that M. had ever specifically considered the question of whether she would wish ANH to be withdrawn if she were in MCS. In holding that it would be ‘wrong to attach significant weight to those statements made prior to her collapse’, he effectively dismissed as irrelevant M.’s former, very clear, views.³⁷ His reasoning was summarised in what Hayden J. called thought-provoking ‘sensitive observations’ regarding the fact that many able-bodied people think that disability must restrict someone’s enjoyment of life, whereas in fact there is a growing ‘awareness that people with disability can experience profound enjoyment of life, within the limitations

²⁹ *Ibid.*, paras 10-11.

³⁰ [2011] EWHC 2443, paras 14, 124.

³¹ *Ibid.*, paras 127, 136, 141, 154, 162, 163, 169.

³² *Ibid.*, para. 148.

³³ *Ibid.*, para. 238; [2015] EWCOP 76 (Fam.), para. 33.

³⁴ [2015] EWCOP 76 (Fam.), para. 70.

³⁵ *Ibid.*, paras 54-55; [2011] EWHC 2443, paras 107, 119.

³⁶ [2015] EWCOP 76 (Fam.), para. 50; [2011] EWHC 2443, para. 119.

³⁷ [2011] EWHC 2443, para. 230.

that their disability may impose', and that 'being comfortable' is a positive experience.³⁸ At one level, Baker J.'s decision can be characterised as leaving options open – it may have been the case that, if M. could have expressed a view, she would have chosen to prolong her life because it included elements of enjoyment – but it also meant that M. had no choice but to continue living a life that Baker J. described as one that 'many would find impossible to accept'.³⁹

There are facts that distinguish *M. v. N.* from *W. v. M.*, but Hayden J. did not state them, nor did he explain how Baker J.'s observations affected his decision. Instead, immediately after quoting those observations, he returned to the judgment of Hoffman L.J. in *Bland* for confirmation that it can sometimes 'be right to cause the death of a human being by deliberately depriving him of food', an opinion that supported his decision.⁴⁰

Hayden J. declined to adopt a 'formulaic "balance sheet" approach' to Mrs N.'s best interests. Instead, he observed that Mrs N.'s attitude to her parents' dementia 'casts a very bright light on what Mrs N. would want for herself in her present predicament', and held that her wishes should prevail:

*However, I am entirely satisfied that Mrs N. would have found her circumstances to be profoundly humiliating and that she would have been acutely alert to the distress caused to her family, which she would very much have wanted to avoid.*⁴¹ (Original emphasis).

This outcome was diametrically opposed to the decision in *W. v. M.*, and gave precedence to Mrs N.'s autonomy. Although Mrs N. was Jewish, there was no suggestion that she believed that God should decide when her life should end. An electronic search of the judgment confirms that the word 'God' does not appear, and there is no allusion to Mrs N.'s religious views or beliefs. Indeed, Mrs N.'s exhortation to 'shoot me' suggests strongly that she believed in self-determination at the end of her life.⁴² Although Hayden J. has broken new legal ground, it is unarguable that he listened carefully to his patient's 'clear voice' and complied with the wishes that she had expressed for herself. In doing so, he respected her autonomy, as statute requires him to do.⁴³

³⁸ [2015] EWCOP 76 (Fam.), para. 66; [2011] EWHC 2443, para. 235.

³⁹ [2011] EWHC 2443, para. 34.

⁴⁰ [2015] EWCOP 76 (Fam.), para. 67.

⁴¹ *Ibid.*, paras 70, 57, 71.

⁴² *Ibid.*, paras 54-55 – see above n. 35.

⁴³ *Ibid.*, para. 59 – see above, n. 23.

5. Hopes for the Future

The major underlying difficulty in cases of this type is that the patient's contemporaneous views cannot be ascertained. Very few people have overcome the distress of envisaging themselves in MCS to the extent that they have discussed whether they would wish to be artificially kept alive in such circumstances. It is therefore highly likely that the best indication of what a patient would wish to happen is his or her past views. As Baker J. pointed out, disabled people may enjoy life more than they had imagined possible when they were able-bodied, so their past views may not represent views that they now hold but cannot communicate to others.⁴⁴

The emerging technique of functional magnetic resonance imaging means that it may one day become possible to 'read' the brain of a completely unresponsive person such as Mrs N. by asking several simple questions such as 'Is your partner's name George?', and instructing her to envisage playing tennis to answer 'yes', and to imagine walking around her home to answer 'no'.⁴⁵ If she responded correctly to such questions, she could be asked about her wishes regarding the continuation of ANH. A great deal of further research is necessary before this approach can be viewed as consistently eliciting reliable evidence, but it may eventually be of significant help to the Court of Protection.

A much simpler technique could, arguably, have been used to try and ascertain M.'s views. She was described as responsive to some external stimuli and able to push a button on request. It therefore seems possible that she could have been asked similar questions, and instructed to push a button to answer 'yes' and to open an eye to answer 'no'. If she were able to respond correctly to the initial questions, she could have been asked about her wishes regarding treatment, removing the need for conjecture.

The present law involves a positive, if imprecise, correlation between the level of consciousness of an uncommunicative patient and the probability that a court will order his or her ANH to be continued. This can be seen as perverse and inhumane, in that patients who are wholly unaware of their circumstances are permitted to die peacefully, while those who are not insensate must continue to exist in circumstances that they may find intolerable. The law should embrace any current and future techniques that enable people at the higher end of the MCS spectrum to contribute to their own life-or-death decisions.⁴⁶

⁴⁴ [2011] EWHC 2443, para. 235 – see above n. 38.

⁴⁵ M. M. Monti et al., 'Wilful modulation of brain activity in disorders of consciousness', *New Engl. J. Med.* 330 (2010), 579-589.

⁴⁶ For a full discussion of the issues, see Paul Catley & Stephanie Pywell, 'The ethical imperative of ascertaining and respecting the wishes of the minimally conscious patient facing a life-or-death decision' in D. Sturma, L. Honnenfelder & M. Fuchs (eds), *Jahrbuch für Wissenschaft und Ethik 2014 Band 19* (Berlin: Walter de Gruyter GmbH, 2015), 77-91.

Hayden J.'s approach to legal precedent and traditional analysis was unorthodox but legally and ethically sound: he focused unblinkingly on Mrs N.'s wishes and feelings, just as the MCA required him to do. By the time of his decision, no one in the court opposed the application, and it seems certain that the outcome was what Mrs N. would have wanted.⁴⁷ The circumstances mean that the decision is highly unlikely to be appealed, so it will become a persuasive precedent for future cases. It is to be hoped that the judges who hear those cases will emulate Hayden J.'s pragmatism, accepting that medical diagnoses and formulaic 'balance sheets' can sometimes prove an obstruction to making the decision that the patient, whose best interests lie at the heart of the case, would have wanted.

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⁴⁷ The Official Solicitor withdrew his opposition after hearing the evidence of Mrs N.'s family – see above, n. 28.

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