

COMMENTARY

DECIDING THE FATE OF A MINIMALLY CONSCIOUS PATIENT: AN UNSATISFACTORY BALANCING ACT?

W v M and Others [2011] EWHC 2443 (Fam)

Introduction

The application in the case of *W v M and others* (hereafter *W v M*)¹ asked the court to authorise the withdrawal of artificial nutrition and hydration (ANH) from a woman in a minimally conscious state (MCS). Tragically, M suffered extensive and irreparable brain damage at the age of 43 following viral encephalitis, which struck her down in February 2003 just as she was preparing to go on holiday with her long-term partner. Since this time M has been entirely dependent on others for her care, including being fed artificially via a gastrostomy tube. Initially M was diagnosed as being in a vegetative state, which has traditionally been referred to as a permanent or persistent vegetative state (PVS).² In spite of the bleak prognosis, for several years M's partner and family, together with the medical team, explored all the possibilities for M's recovery, but eventually it was decided by the family that as M's prospects were hopeless, it would be in her best interests to have all life-sustaining treatment withdrawn. At this point, they applied to the High Court for an order to withdraw ANH in accordance with the requirement set down in the case of *Airedale NHS Trust v Bland*.³ However, during the course of the subsequent investigations to confirm M's diagnosis for the purposes of the application, it was discovered that in fact M was not vegetative, but rather in a state of minimal consciousness (MCS).

Had M's initial diagnosis of PVS proved accurate, authorisation to cease ANH would have been uncontentious. As Mason and Laurie have observed, once the diagnosis of PVS is confirmed, 'the conclusion follows automatically that the patient's best interests dictate the termination of assisted feeding'.⁴ This was echoed by Baker J when he said, '[I]n VS cases, the balance falls in one direction every time – in favour of

¹ [2011] EWHC 2443 (Fam).

² A vegetative state is where the patient is believed to be completely insensate, with no consciousness and no prospect of becoming conscious.

³ [1993] 1 All ER 821, (1993) 12 BMLR 64, Fam Div, CA, HL.

⁴ JK Mason and GT Laurie, *Mason and McCall Smith's Law and Medical Ethics* (8th edn Oxford University Press, Oxford 2011) 510.

withdrawal'.⁵ But as a patient with some degree of consciousness, M possessed the ability to derive some benefit from her life and so a careful balancing exercise was required in order to determine whether it was in M's best interests to have ANH withdrawn. Opposing the application, the Official Solicitor (on behalf of M) submitted that for a person in MCS who is clinically stable, the balance sheet approach is inappropriate as it can never be in such a person's best interests to have ANH withdrawn. Moreover, that any such withdrawal of life-sustaining treatment would amount to murder, as well as a breach of the European Convention on Human Rights, with respect to Articles 2, 3, and 8.⁶ If, however, a balance sheet exercise is deemed applicable, the Official Solicitor argued that such should result in favour of maintaining M's life.

Ultimately, while the court rejected the argument about the inapplicability of the balance sheet approach to such a question, it was agreed that the balancing exercise weighed in favour of maintaining life. For Baker J, the crucial distinction between a patient in PVS and one such as M—in MCS and thus able to experience some pleasure (and pain) from her existence—provided the decisive reason for ruling that the argument in favour of preserving life should be determinative in the face of such a dilemma. Accordingly, the application was rejected and M lives on. With conflicting evidence and consequent uncertainty over quite how much pleasure in comparison to suffering M actually experiences, Baker J chose to effectively disregard the evidence as to what M would have wanted had she been able to contribute to the decision, instead opting to maintain her life in circumstances that her family are sure she would have found objectionable.

W v M raises a number of profoundly important medico-legal and ethical issues. This case note will outline the medico-legal background, before the balancing exercise carried out in *W v M* is considered. This invites the question of whether, and how far, a balancing exercise conducted in the shadow of sanctity of life concerns can be compatible with the requirement designed to accord respect to the previously expressed wishes of an incompetent person, as set out by the Mental Capacity Act 2005.

⁵ Above n 1 at 35. Although note that the court must nevertheless weigh the advantages and disadvantages.

⁶ Article 2 protects a right to life. Article 3 provides a right to protection from torture or inhumane or degrading treatment or punishment. Article 8 provides a right to respect for private and family life. It was also submitted that, depending on the circumstances, such a withdrawal of ANH could also amount to a breach of Articles 13 and 14 (see *W v M*, above n 1, para 36).

Background

Before appraising the court's decision in *W v M*, it is useful to first consider the medico-legal context of the case. The condition known as MCS has only been recognised relatively recently as medical science has explored the vegetative state.⁷ MCS is described as:

... a state just above that of vegetative state, but which also involves extremely significant limitations on consciousness with a quality of life that many would find impossible to accept were they able to consistently express themselves with full competence.⁸

While *W v M* represents the first time the fate of a patient in MCS has been expressly considered in this way, it is highly likely that some of the patients treated as being in PVS, who have had ANH withdrawn pursuant to the ruling in *Bland*, were in fact in MCS or a similar condition. For example, in *Frenchay Healthcare NHS Trust v S*,⁹ the court authorised the discontinuation of treatment despite uncertainty over the patient's diagnosis.¹⁰ Not only did the applicants fail to obtain any independent evidence as to S's condition,¹¹ but since S demonstrated restlessness and distress that seemed inconsistent with PVS, there was a significant doubt about her true condition. Likewise, in *Re H*,¹² the patient seemed to possess a level of consciousness beyond that of PVS, but nevertheless the court ruled that cessation of treatment was lawful. Despite accepting that H's condition did not fit the diagnosis of PVS set out in the guidelines established by the Royal College of Physicians, Stephen Brown ruled that it was in the best interests of the patient to have life-sustaining treatment concluded, stating that; '[T]he sanctity of life is of vital importance. It is not, however, paramount'.¹³

⁷ See, for example, A Owen and MR Coleman, 'Functional Neuroimaging of the Vegetative State' (2008) 9 Nat Rev Neurosci 235, and L Skene and others, 'Neuroimaging and the Withdrawal of Life-Sustaining Treatment from Patients in Vegetative State' (2009) 17 Med L Rev 245–61.

⁸ *W v M* (above n 1) para 34.

⁹ [1994] 2 All ER 403.

¹⁰ In *Frenchay*, the patient's feeding tube accidentally became detached, which prompted the application to discontinue treatment. For further discussion, see M Brazier and E Cave, *Medicine, Patients and the Law* (5th edn Penguin, London 2011) 571.

¹¹ This is required under condition three of the four set down in *Bland*. The others are that every effort should be made to provide rehabilitation for a period of at least six months, diagnosis of irreversible PVS should not be confirmed until at least twelve months after the injury and finally, that the views of the patient's immediate family will be given great weight (per L Goff, *Bland* (above n 3) para 870–871).

¹² *Re H (Adult:IncompetentPatient)* (1997) 38 BMLR 11.

¹³ *Ibid* at 16.

This approach is also sanctioned by the British Medical Association in their guidance on withholding and withdrawing life-prolonging medical treatment, which expands the ratio of *Bland* by sanctioning withdrawal from patients with other non-terminal conditions such as severe dementia or stroke victims.¹⁴ Moreover, generally it is accepted practice to withdraw a treatment that is no longer in the best interests of an incompetent terminally ill patient,¹⁵ or even a seriously ill or injured patient for whom doctors have effectively ‘interrupted’ death. In the latter example, this will often be at a stage when the patient is in intensive care, ventilator dependant, and for whom the prospects of recovery look very bleak. Kitzinger and Kitzinger have explored the way in which the ‘window of opportunity’ for allowing death after severe brain injury or illness becomes progressively narrower as the level of medical intervention required to maintain life decreases.¹⁶ Effectively, this means that a ventilator-dependent patient may be permitted to die by withdrawing ventilation if an early decision (that he/she will not make a satisfactory recovery) is made. But if a decision is made to ‘wait and see’ in order to explore the patient’s chances of recovery, the opportunity for allowing death will decrease or disappear, as it has for M.

M’s Situation

It seems likely, therefore, that M’s condition shares similarities with patients who have been treated as if they were in PVS. Recent clinical advances, however, have enabled more accurate diagnosis and so M’s precise condition has been scrutinised. Notable amongst the recent advances is a diagnostic assessment known as SMART,¹⁷ a structured sensory stimulation programme where responses are observed and recorded, which was utilised in *W v M* to assess M’s condition.

Initially, in 2007 when the court application began, a SMART assessment was undertaken on the instructions of the Official Solicitor’s medical expert,¹⁸ following which M was diagnosed as being at a moderate level of MCS. During the assessment, M showed some ability to obey commands—to press a buzzer—which prompted the experts to

¹⁴ *Withholding and Withdrawing Life-Prolonging Treatment. Guidance for Decision Making* (British Medical Association, 2007).

¹⁵ See, for example, *Burke v UK* (App No 19807/06) (2006).

¹⁶ C Kitzinger and J Kitzinger, ‘Some families’ experiences of decision-making after severe brain injury: Reflections on the ‘window of opportunity’ for withholding or withdrawing life-sustaining treatments’ (2012) *Sociol Health Ill* (forthcoming).

¹⁷ SMART stands for ‘Sensory Modality Assessment and Rehabilitation Technique’.

¹⁸ Mr D Badwan, a former neurosurgeon and expert in clinical rehabilitation.

hope that M might develop the means to communicate. Accordingly, it was recommended by the joint experts that M be transferred to the Royal Neurological Hospital in Putney in order to explore the possibilities for developing M's ability to communicate. Unfortunately however, M did not make the advances that the doctors had hoped for and at the conclusion of M's stay in Putney it was reported that M's responses remained non-functional. Thus M was admitted to a care home, where she remains to this day.

In 2009, M's mother instructed a further expert, Professor Turner-Stokes, to assess her daughter to determine whether, in light of M's condition being confirmed as MCS rather than PVS, it was appropriate to continue the application to withdraw ANH. While Professor Turner-Stokes' report concurred with the SMART result on the diagnosis of MCS, in contrast with the earlier assessment, Professor Turner-Stokes concluded that M was at the lowest level of MCS, effectively on the borderline of PVS. Professor Turner-Stokes also reported that M suffered from hypersensitivity as well as 'a significant level of discomfort and, on occasions, pain'.¹⁹ This view prompted M's family to continue the application and thus, the proceedings were transferred to the new Court of Protection, which was established to deal with such cases pursuant to the Mental Capacity Act 2005.

Because M's condition, therefore, is functionally above that of a vegetative person, she has interests which need to be weighed to determine whether withdrawing ANH is in her best interests: effectively, whether it is better for her to continue living or better for her to die. Legally, for patients such as M who lack mental capacity, decisions such as this fall within the jurisdiction of the Mental Capacity Act 2005, with such dilemmas being resolved in favour of whichever course of action is deemed to be in the patient's best interests.²⁰ Endorsing a balance sheet approach, the Act facilitates a proactive methodology which encompasses 'medical, emotional and other issues' beyond the purely clinical aspects of determining best interests.²¹ Thus, the decision fell to be determined upon a range of factors affecting M's quality of life such as her clinical condition, the prognosis for future pleasurable experiences weighed against negative experiences, together with the social and emotional factors relevant to M's situation.

¹⁹ *W v M* (above n 1) para 24.

²⁰ Section 1(4) provides the key principles that: 'an act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests'.

²¹ *Re A (Medical Treatment: Male Sterilisation)* [2000] 1 FCR 193, CA, at 200.

The Balancing Exercise

On the question of M's clinical prognosis, it is expected that M, who, at the time of the hearing, was aged 52 and clinically stable, might live for approximately 10 years provided illness or disease does not end her life. With respect to her physical condition, M suffers pain and distress as a consequence of severe spastic tetraparesis (which causes limb deformity), incontinence and she needs to be regularly repositioned to avoid bed sores. While there may be a negligible chance that M could emerge from MCS, the prospects of recovery after so many years are extremely remote. Following the most recent SMART assessment in 2011, it was reported that M has maintained approximately the same status of MCS since 2007.

In addition to the clinical assessment, section 4(6) of the Mental Capacity Act 2005 provides that the proxy decision-maker should, so far as possible, consider: (a) the person's past and present wishes and feelings, (b) the beliefs and values that would be likely to influence the decision if the person had capacity, and (c) other factors that the person would be likely to consider if he were able to do so. Furthermore, section 4(7)(c) of the Act provides that the views of anyone engaged in caring for the person or interested in his welfare must be taken into account.

Applying these factors to M's case, her partner (S), together with her sister (B) and previously her mother (W),²² provided evidence that M would strongly object to such a life of total incapacity and dependence in a residential home and would thus choose to die rather than endure such an existence. For example, M's sister, B, provided a moving account of M, describing how she had been an active, lively, and fiercely independent person who, at various times in her life, such as when their father and grandmother were taken into residential care, and similarly at the time that Tony Bland's case was in the media, had expressed the view that death would be preferable to such an existence. M's family also provided evidence to M's current quality of life, expressing the view that M's existence is overwhelming devoid of pleasurable experiences and that as '... a very proud person ... she would be horrified that she was carrying on in this undignified manner'.²³

Clearly, as the court discussed,²⁴ the observations of M's family do not amount to a legally binding advance decision under the Mental Capacity Act 2005,²⁵ and, as Donnelly has observed:

²² During the course of the case, W became too ill to continue the legal battle to allow her daughter to die.

²³ At para 119.

²⁴ *W v M* (above n 1) paras 83–85.

²⁵ Sections 24, 25 and 26 of the MCA set out the legal requirements for any advance refusal of treatment.

Statements such as ‘I would rather die than be dependent’ may reflect a desire for reassurance, or may be a result of temporary depression or fear, and may not represent the person’s considered views on future care should they lose capacity.²⁶

While there is no evidence that M was afraid, depressed or seeking reassurance at the time she expressed her views, as recalled by her sister, it is of course possible that M had not fully considered whether she would wish to remain alive in MCS. On balance however, M’s views seem quite clear. She stated them on more than one occasion and in relation to different scenarios and so it is unfortunate that Baker J chose to effectively disregard this evidence. Moreover, in view of the fact that Baker J himself described the condition of MCS as one which involves, ‘... a quality of life that many would find impossible to accept’,²⁷ his objective view of life in MCS, coupled with the clear evidence from M’s family should arguably have enabled him to accord more respect to M’s autonomy.

Bringing to a close the discussion of M’s family’s evidence, it should of course be noted that the motives of the next of kin in such a case must be scrutinised. Throughout the years of M’s illness, all concerned had devoted themselves to M and so there is no reason to doubt that M’s family and partner had anything other than M’s best interests in mind. While it might be observed that M’s death would release them from any duty towards M and also would release them from the suffering which they endure as a consequence of their distress over M’s predicament, as the court observed, there is nothing to suggest they have acted from selfish motivation.²⁸

Assessing M’s quality of life was a particularly difficult aspect of the case. While it is generally agreed that people in MCS do experience sensation, there are significant challenges in interpreting the evidence.²⁹ For example, evidence that M might have smiled was described as speculative since this could equally have been a grimace. We do know, however, that in comparison to patients in PVS, those in MCS are able to experience both pleasure and pain, prompting some to question the assumption that being in PVS is necessarily a worse fate than being in MCS. For example, Ashwal and Cranford have argued that being in MCS is

²⁶ M Donnelly, ‘Best Interests, Patient Participation and the Mental Capacity Act 2005’ (2009) 17 *Med L Rev* 1–29.

²⁷ *W v M* (above n 1), para 34.

²⁸ For example, para 117.

²⁹ See, for example, A Demertzi and others, ‘Different Beliefs about Pain Perception in the Vegetative and Minimally Conscious States: a European Survey of Medical and Paramedical Professionals’ (2009) 177 *Prog Brain Res* 329–38.

worse than being in PVS because the person can experience both pain and some awareness of their condition.³⁰ As noted above, the applicant's expert reported that M was likely to be experiencing significant suffering, but in contrast, the opposing expert reported that M's quality of life 'is reasonable and could be further improved taking into account recommendations made for future management'.³¹

The staff at the care home where M resides provided further evidence of M's day-to-day experiences. A number of carers and other medics contributed their view and, to summarise this evidence, it seems that M derives some pleasure from aspects of her life as well as suffering some discomfort, pain, and distress from other aspects of her life. For example, one care worker reported that M moans when uncomfortable and when asked whether she thought that M experiences pleasure, answered that, 'she found it difficult to say if M gets any pleasure from anything'.³² In a slightly diverging account, a couple of those involved in M's care reported that on occasion M has changed her facial expression into what seemed like a smile, and that she seems to derive enjoyment from the time spent in the snooze room,³³ or from listening to music, or in response to certain people. Others reported that M can become distressed when listening to music. One carer estimated that M experiences approximately three good days out of ten and that she seemed to be in pain, distress, or discomfort for about 30% of the time.

On the question of M's responses, it was observed by several staff that M will on occasion look at things when instructed to do so, but that she will close her eyes if she seems to notice that someone is looking at her. This echoes the observation of the hospital in 2007 that M 'squeezed her eyes tightly shut most of the time' due to hypersensitivity.³⁴ M was reported to have had some awareness of outings, with mixed reactions to wind and sun. Some of the people involved in M's care have also reported that M has spoken on occasion,³⁵ although there is no functionality to these isolated incidents. Overall, those responsible for M's residential care were either not in favour of withdrawing ANH or were neutral on this question. On this subject, Heywood has observed, 'with the greatest respect, their close involvement with the patient and

³⁰ S Ashwal and R Cranford, 'The Minimally Conscious State in Children' (2002) 9 *Sem Pediatr Neurol* 19–34.

³¹ *W v M*, para 26.

³² *W v M*, para 139.

³³ A room at M's care home which is designed to give sensory pleasure via lights and music etc.

³⁴ See, for example, para 182, although note that the evidence put to the court by Mr Badwan on behalf of M suggested that there was no evidence of hypersensitivity (at 197).

³⁵ For example, she is reported to have said 'bloody hell', 'hello', and 'where am I?' on separate occasions. See para 174.

her situation may have clouded their judgment about M's sense of enjoyment in her life'.³⁶

In weighing the evidence and accounts of M, determining precisely whether, on balance, pleasure outweighs pain or vice versa seems impossible as many of M's responses are open to interpretation. Thus, any conclusion should arguably point towards an unknown ratio of pleasure to pain which might only be estimated in the region of 50/50. Accordingly, Baker J's summation that he does not 'accept that her experiences are wholly, or even on balance negative' seems to be founded on optimism rather than the evidence provided to the court. While it should be noted that allowing assessments of this nature to lead to life-terminating decisions can be potentially dangerous,³⁷ in *W v M* the court had a clear indication of what M would have preferred and yet Baker J chose to discount this evidence. As Heywood has pointed out, this approach is 'a rather narrow way of looking at best interests'.³⁸

Interestingly, the court ordered that the current Do Not Resuscitate Order should remain and further, that if M should succumb to infection requiring antibiotics for example, the decision whether to treat should be left to clinicians in consultation with the family and carers. Consequently, it appears that the court was not unequivocally opposed to the view that it is not in M's best interests to be treated, but rather the nature of the treatment is key to the question of whether it should occur. This reflects the Kitzingers' observations over the opportunistic nature of decisions which might allow death.³⁹ Clearly, one of the key arguments in favour of not sanctioning withdrawal of ANH is that to do so would be painful and distressing, albeit that this could be ameliorated via appropriate end-of-life care. As Heywood has noted:

[T]his feeds into a much wider debate about why the law should condone certain passive inactions, but fail to sanction any positive steps to hasten a patient's death and put an end to their pain and suffering.⁴⁰

Conclusions

In the face of uncertainty over M's quality of life, Baker J essentially had a choice between prioritising M's autonomy or prioritising the

³⁶ R Heywood, 'Withdrawal of Treatment from Minimally Conscious Patients' (2012) 7 Clin Ethics 10.

³⁷ See, for example, GT Laurie and JK Mason, 'Negative Treatment of Vulnerable Patients: Euthanasia by Any other Name?' [2000] 3 Juridical Rev 159–178.

³⁸ R Heywood, above n 36.

³⁹ Discussed above, above n 16.

⁴⁰ R Heywood, above n 36.

preservation of life. While the role of the court is to protect the interests of incompetent people—so where there is doubt as to the person's best interests, protecting life rather than choosing death, may seem to be the least worst option—this inclination should not override the legal obligation to accord respect to the wishes of the incompetent patient. Where there is good reason to doubt that a person has a reasonable quality of life, together with clear evidence that the person would not choose life if they were able to communicate, sanctity of life concerns should not overshadow the other factors. As Mason and Laurie have opined, 'it is surely not in a person's best interests to have his or her explicit or implicit preferences ignored'.⁴¹ By prioritising the preservation of life over respecting M's known wishes, Baker J has effectively disregarded the requirement to give weight to the person's past feelings and beliefs, as well as the views of her family, under the Mental Capacity Act. While this decision does not create a precedent, anyone wishing to avoid being kept alive in the event that accident or illness causes terrible brain damage should take note: nothing short of a legally binding advance directive will protect the incompetent patient from a fate such as M's.

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⁴¹ Mason and Laurie, above n 4, p 516.

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