The Right to Die for Patients in a Minimally Conscious State: A Review of the Decision in W v. M

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Abstract

The right to die has been subject to increased media attention in recent years due to a surge in cases in which courts are required to make decisions on whether to approve the right to die or deny it. Courts have been very consistent in denying terminally ill patients the right to end their suffering through assisted suicide. This paper examines the court decision in *W v. M* (2011) on the right to die for patients in a Minimally Conscious State. In this case, the court weighed up a number of factors such as the patient's past wishes and feelings before reaching their decision. These factors are critically examined in order to provide clarity on the court's position in cases involving patients in a Minimally Conscious State.

Keywords: Right to die, terminally ill, minimally conscious state, court case.

Essay

The right to end life-sustaining medical treatment for persons in a Minimally Conscious State (MCS) has been at the centre of medical law and ethics debates for over a century now (Johnson, 2011). Despite the debates, sanctity of life has been the orthodox position since the passing of the Suicide Act 1961, which made it unlawful in England and Wales to "aid, abet, counsel or procure the suicide of another."[1] The case of *W v. M*[2] has been the first of its kind in the English jurisdiction where the

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[1] Section 2(1).

[2] (2011) E.W.H.C. 2443 Fam 28th September 2011.

Court of Protection has been asked to authorise withdrawal of artificial nutrition and hydration (ANH) from a patient in a MCS. The MCS was first identified and defined by the Aspen Neurobehavioural Conference Workgroup as, "a condition of severely altered consciousness in which minimal but definite behavioural evidence of self or environmental awareness is demonstrated" (Giacino et al., 2002, pp. 350-1). In England and Wales, it is lawful to withdraw ANH and other life sustaining treatment from an incompetent patient under the Mental Capacity Act (MCA) 2005 and the MCA Code of Practice 2008, if it is in the patient's best interest not to have the treatment continued (Skene et al., 2009).

In *W v. M,* Baker J objected to the withdrawal of ANH from a patient diagnosed as being in a MCS, despite her family's wishes to have the treatment withdrawn. *M's* family wanted ANH withdrawn so that *M* could be allowed to die. Baker J considered the role of clinicians, family members and carers in healthcare decision-making and critically evaluated Human Rights provisions before reaching a decision, which could have implications for legal development. Would this case have been decided differently had *M* made an advance decision or had she appointed a Lasting Power of Attorney (LPA) prior to the circumstances that later arose? These legal and ethical issues are explored in this paper.

Due to *M's* incapacity, she was unable to make a decision on her care needs because there was an impairment or disturbance in the functioning of her mind or brain.[3] At the heart of the MCA 2005 lies the principle that where the individual lacks capacity, any decision or action taken on their behalf must be in their best interest.[4] Best interest standards were examined in light of participative elements introduced in the MCA, conclusively attaching greater weight to sanctity of life, which was of profound and significant importance. In *W v. M*, Baker J applied the balance sheet approach proposed by Thorpe J in *Re A (male Sterilisation)*[5] by weighing up the benefits and drawbacks of withdrawing ANH for a patient in MCS. The decision in *NHS Trust v. MB*[6] confirmed that even if the burdens of continuing treatment outweighed the benefits, treatment could be continued if it was in the patient's best interest. This balance sheet approach has shifted the best interest

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[3] Mental Capacity Act 2005, Section 2(1).

[4] Section 1(5).

[5] (2000) 1 F.L.R. 549.

[6] (2006) EWHC 507 (Fam).

perspective to a necessary requirement in the decision-making process. However, Bartlett (2005) calls for a more substantive or least content filled test.

Three key factors were weighed up by Baker J in *W v. M.* First and foremost, Baker J invoked statute when deciding the best interest element by referring to Article 2 of the European Convention on Human Rights 1950 (ECHR), which gives everyone a right to life. Baker J also relied on the ruling in *NHS Trust A v. M*[7] where it was decided that withholding or withdrawing medical treatment would not constitute an intentional deprivation of life in breach of Article 2. The court held that there was no duty under Article 2 to provide futile treatment.[8] In exploring futility, the General Medical Council (GMC) guidelines on good decision-making in end-of-life decisions do not impose an obligation to give treatment that is futile or burdensome (GMC, 2010). This is also found under the MCA Code of Practice 2008, paragraph 5.31 and was reinstated in *Airedale NHS Trust v. Bland*[9] where Lord Goff held that "the fundamental principle is the principle of the sanctity of human life." A core element of medical practice is that doctors must never have the option to suggest a course of action that would harm their patients (British Medical Association, 2009). Patients trust their doctors that the treatment and advice they receive will always be in their best interest. Thus acting with the primary intention to accelerate a patient's death is difficult to reconcile with the ethical principles of beneficence and non-malfeasance.

M's mother and sister argued that her life was of "pointless existence" (Ward, 2011). A physician observed that some patients "suffer severely at the end of life" and agreed that patients can still experience "anguishing deaths" in spite of the "heroic efforts" of health professionals (McKhann, 1999, p. 79). In support of these observations, one patient stated that their experience with terminal suffering was so intense that they felt as though they were becoming "less of a human being" (Kübler-Ross, 2001, p. 61). However, in *M's* case, observations from clinicians, doctors and carers proved otherwise. On that basis, Baker J accepted that *M* did have "some positive experiences" (Kübler-Ross, 2001, p. 61) which did not amount to treatment being futile.

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[7] (2001)1 All E.R. 801.

[8] *NHS Trust A v. M* (2001) 1 All E.R. 801.

[9] (1993) A.C. 789 as per Lord Goff, 'if treatment is futile, it is no longer in the patients best interests to continue it'.

The decision in *Pretty v. UK*[10] confirmed that Article 2 did not give a person a right to die. Dianne Pretty had motor neurone disease and she wanted to end her life. She was unable to kill herself due to the incapacitating nature of her illness. She asked the Director of Public Prosecutions (DPP) to give her husband advance immunity from prosecution. The court held that Article 2 cannot be interpreted as giving a right to die. Thus the case established that a person cannot obtain advance immunity from prosecution. This was affirmed by the MCA Code of Practice 2008, paragraph 5.31 which stipulates that all reasonable steps must be taken to prolong a person's life.

However, *W v. M* was distinguished because *Bland* was in a vegetable state (VS). Unlike *Bland*, *M* "was sensate, clinically stable, aware of herself and her environment, able to respond to people, and to music, and also, in a very limited way, able to communicate about her needs." *M* was recognisably alive, treatment was neither futile nor burdensome and thus it was in her best interest to be kept alive.

Second, *M's* past wishes and feelings were considered in determining best interest. The MCA 2005 requires the court to consider, so far as is reasonably ascertainable, the person's past and present wishes or feelings.[11] Past wishes might also be ascertained from relatives and others known to the patient. In this case, *M's* partner and sister based their arguments on informal statements which included "*M* visiting her father and grandmother in a nursing home and stating she would not want to live like that, would not want to be dependent on others, wanted 'to go quickly', and that someone in a condition as *Bland* should be allowed to die". Notably, *M's* family argued that, "she would not have wanted to live in the condition that she is in". The question for the court was therefore how much weight they should attach to past wishes and feelings in the absence of an advance decision.

When it comes to advance decisions (or directives), there is no requirement that oral statements must be written, although a written statement could carry evidential weight in end-of-life decision-making (Samantha, 2009). Baker J accepted these views and held that there was no evidence to suggest that "*M* ever specifically considered the question of withdrawal of ANH, or ever considered the question whether she would wish such treatment to be withdrawn if in a MCS". Similarly, in

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[10] (2002) 35 E.H.R.R. 1.

[11] Section 4(6).

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W Healthcare NHS Trust v. H,[12] it was held that in absence of an advance directive clearly demonstrating *H's* preference of being deprived of food and drink until she died, it was in her best interest to reinsert the tube. This clearly shows that in order to prevent ambiguities in law, the Court follows a strict approach in deciding what weight should be given to informal statements in end-of-life decisions. If they bear no similarity to the current circumstances, they will be irrelevant in end-of-life decision-making. Furthermore, *M's* present wishes could not be known since she had been in a MCS for eight years.[13] Arguably, ascertaining current views from an incapacitated person is problematic, and in all probability is inspirational rather than realistic. Baker J critically evaluated all these issues and held that, in the absence of an advance decision, it would be wrong to attach significant weight to statements made by *M* prior to her collapse.

In this case, emphasis was put on *M* not having made an advance decision, which poses the question: had one been in place, would this case have been decided differently? If an advance decision had been made by *M*, provided it fulfilled both the common law and statutory requirements under the MCA 2005[14], it would have been binding. This would have allowed her to refuse treatment in anticipation of a period of incompetence when she lacked the ability to make a contemporaneous decision in the future. The GMC guidelines state that "[a]ny valid advance refusal of treatment - one made when the patient was competent and on the basis of adequate information about the implications of his/her choice, is legally binding and must be respected where it is clearly applicable to the patient's present circumstances and where there is no reason to believe that the patient had changed his/her mind" (GMC, 2002, p. 5).

Nevertheless, it is very unlikely that *M* would have made an advance decision because she had enjoyed a healthy and independent lifestyle. The viral encephalitis, which left her with extensive and irreparable brain damage, was a result of unforeseen circumstances a layperson would never have predicted. Legal commentators such as Maclean (2008, p. 16) argue that "one of the well-known problems with advance directives is the difficulty of drafting a sufficiently specific directive that anticipates the future circumstances when the individual would like treatment to stop." Arguably, this is a more straightforward approach for a patient with an illness that is inherited, as

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[12] (2005) 1 W.L.R. 834.

[13] Mental Capacity Act 2005, section 4(6).

[14] Sections 24, 25 & 26.

the patient knows the exact circumstances to outline in the advance directive. However, for a formerly healthy patient like *M* it becomes very difficult to draft an advance decision based on unforeseen circumstances. Furthermore, advance directives often do not achieve the individual's aims due to the need to satisfy the validity and applicability requirements to the satisfaction of the reasonable belief of the healthcare provider. Considering *M's* healthy lifestyle as well as the difficulties associated with drafting an advance decision, it is very unlikely *M* would have made one prior to the circumstances that later materialised.

Preferably, while *M* was competent, she could have appointed her partner and sister as her LPA[15] to make healthcare decisions in her best interest. The MCA 2005 allows an adult with capacity to select a trusted and willing person over the age of 18 to make healthcare and welfare decisions on their behalf in the event of loss of capacity.[16] However, the decision-making authority of an attorney does not extend to decisions about life-sustaining treatment unless the instrument contains an express provision to that effect.[17] Without such a definite expression of will, there would very likely have been irreconcilable disagreements between the attorneys (*M's* partner and sister) and the healthcare professionals over what would be in *M's* best interest, thus the case would have had to be referred to the Court of Protection for adjudication. The attorneys would argue that it is in *M's* best interest to have ANH withdrawn while the health care team would probably want treatment to continue. Provisionally, *M* would be given life-sustaining treatment to prevent a serious deterioration in her condition while adjudication is sought.[18] If *M* did not include life-sustaining treatment in the instrument, there is little chance that requests for withdrawal of ANH expressed to her attorneys would be respected, unless this is deemed to be in her best interest by the medical team. However, if the life-sustaining treatment provision were included in the instrument, the attorney's plea to withdraw ANH to allow *M* to die would have been successful.

Third, pain was another factor considered when determining best interest. An Abbey Pain Scale test confirmed that *M* was suffering pain, but the frequency of pain or discomfort was unclear. This test is used to measure pain in people with end-stage dementia who cannot verbalise (Abbey et al.,

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[15] Mental Capacity Act 2005, section 9.

[16] Section 10.

[17] Mental Capacity Act 2005, section 11(8).

[18] Mental Capacity Act 2005, section 6(7) (a) (b).

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2004). *M's* carers reported that *M* was in pain 25-30 per cent of the time, but her family were certain that the pain was a more frequent occurrence. Baker J accepted that *M* being in a MCS had to experience pain, but the extent of the pain was not known. He concluded that there are times when she experiences pain and times when she is pain-free. He also pointed out that pain relief medication is available for times when *M* is in pain and that evidence suggested that she was not in extreme pain. *M* could at times feel pain and occasionally vocalised the experience, which was not applicable to *Bland,* who was in a VS. This signifies that carers, clinicians and doctors play a role in end-of-life decisions. All their views, findings and evidence are given due weight by the court.

Moreover, quality of life was also considered when determining best interest. In examining *M's* quality of life, Baker J pointed out that she was no longer able to enjoy life considering her independent life-style, and it was wholly understandable why members of her family thought she did not enjoy life at all. Notably, *M's* sister *B* stated that, "she cannot enjoy a drink, a cup of tea or anything. She has got no pleasures in life". Was *M's* quality of life therefore so poor, the burden of the MCS so great, to justify withdrawal of ANH? Baker J decided to explore this issue further by considering the evidence from clinicians, doctors and *M's* carers. The carers submitted that *M* did enjoy some aspects of her life because she occasionally smiled, cried when certain music was playing and overall had some positive experiences. Although her prospect of recovery was very remote and she was likely to stay in this state for the rest of her life, and while Baker J accepted that many of her experiences were negative, he did not find her current life to be overwhelmingly negative or overly burdensome.[19] Distinctively, *Bland* had such a poor quality of life that continuation of treatment was of no benefit to him.

In exploring the notion of dignity, Baker J held that there is dignity in the life of a disabled person who is being well cared for and kept as comfortable and pain-free as possible. Article 3 of the ECHR provides a prohibition on inhuman and degrading treatment. Furthermore, *NHS Trust A v. M*[20] confirms that the patient must be aware of the inhuman or degrading treatment experienced. Arguably, *M* would have been aware if ANH was withdrawn and died from starvation and dehydration within 2-3 weeks since she had a minimal level of consciousness. This infringement of Article 3 does not amount to a dignified end-of-life thus it was not justifiable to have ANH

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[19] MCA Code of Practice, para 5.31.

[20] (2001) 1 All E.R. 801.

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withdrawn. Wishes and feelings of family members and carers were also considered in analysing best interest. Section 4(7) of MCA 2005 allows the court to consult the views of anyone engaged in caring for *M* or interested in her welfare. A majority of *M's* carers argued that it was in her best interest to be kept alive as she had some positive experiences. However, *M's* family wanted ANH withdrawn, so that *M* could be allowed to die. *Glass v. UK*[21] confirmed that Article 8 of the ECHR involved parents being involved in decisions regarding their children's welfare. In relation to *M*, the Court of Protection had so far as practically possible involved her family in the decision making process, thus there was no infringement of Article 8.

Having weighed up and analysed all the factors in relation to best interest, the demerits of continuing ANH outweighed the merits. Baker J held that sanctity of life was the decisive factor in this case, objecting to the withdrawal of ANH. Being in a MCS, it was in *M's* best interest to be kept alive though a do-not-resuscitate order was upheld.

The decision in *W v. M* could have implications for legal development. First, it gives more support to the argument that the right to die should be outlawed because of the sanctity of human life. It is based on the belief that human life should be protected at all times and should be cared for throughout their lives (Holt, 2008). It is also morally and ethically wrong to pass legislation that is grounded in the belief that some people are better off dead; to approve the right to die would undermine all the fundamental principles underpinning the sanctity of life. On that basis, the law should not be used as a vehicle for the right to die. Second, *W v. M* challenges previous decisions concerning patients' plans to go abroad for the purpose of assisted suicide because where the law throws out the right to die through the door it would otherwise allow it back in through the window. This was evident in *Local Authority v. Z*[22] where it was held that the law did not penalise the decision of a competent adult to take her own life. *Z* suffered from an incurable degenerative brain disease and wished to travel to Switzerland for assisted suicide. Her husband informed the Local Authority that she was proposing to make the necessary arrangements. The court held that if

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[21] (2004) Lloyd's Rep. Med. 76.

[22] (2004)E.W.H.C. 2817Fam.

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a person has capacity, there is no basis in law for preventing her from planning to go abroad for the purpose of ending her life.

Furthermore, the right to go abroad for assisted suicide can only be supported if there is unavailability of first class services to alleviate the desire for a patient to end their life. One health professional observed that even a "well planned death" can be "slow, noisy, upsetting, and unpleasant to witness" (Humphry, 1992). However, he believed that the focus should be on meeting the palliative care needs of patients in order to ensure the provision of appropriate pain control, dignity and comfort rather than clinically assisting suicide.

It can therefore be seen that the decision in *W v. M* has brought some degree of clarity over the right to end life-sustaining medical treatment for persons in a MCS. Before reaching a decision, Baker J weighed up the benefits and drawbacks of withholding life-sustaining medical treatment by using the balance sheet test to determine *M's* best interest. However, Barker J placed more weight on the ethical principle of sanctity of life which is supported by Article 2 of the ECHR. The degree of pain experienced and quality of life enjoyed were also considered. Although relatives argued that *M's* pain was more severe and frequent, the medical professionals disagreed. However, there was a general agreement that *M* could no longer enjoy life. Barker J relied on the legal effect of *M's* past wishes to reach the decision. There is no requirement for past wishes to be in writing, which creates doubt and ambiguity over their correctness.

Alternatively, the patient could have drafted an advance directive. However, drafting an advance decision is very difficult, especially since the patient is unlikely to know future outcomes. Despite that, if an advanced directive that fulfilled both common law and statutory requirements was made by *M*, it would have been binding. Similarly, if a LPA contained an express provision that extends decision making authority to life-sustaining treatment, then a challenge by health professionals would have been avoided and the LPA's decision would have been allowed to stand. In *W v. M*, a LPA would have offered a more flexible solution than an advance directive, which is constrained by requirements of applicability and validity in end-of-life decision-making, provided the LPA's provisions were precise enough.

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Overall, *W v. M* has set a precedent with regards to withdrawing life-sustaining treatment for persons in a MCS. It has removed ambiguity about how the law approaches withdrawal of treatment for patients who are not in a VS following *Bland*. Despite the legal developments, reaching the right decision is crucial because an erroneous decision to withdraw life-sustaining treatment that results in death is irreversible.

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