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How to cite:

Catley, Paul and Pywell, Stephanie (2016). The ethical imperative of ascertaining and respecting the wishes of the minimally conscious patient facing a life-or-death decision. In: Sturma, D.; Honnefelder, L. and Fuchs, M. eds. *Jahrbuch für Wissenschaft und Ethik*. Band 19, 19. Berlin: De Gruyter, pp. 77–90.

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Version: Accepted Manuscript

Link(s) to article on publisher's website:

<http://dx.doi.org/doi:10.1515/jwiet-2015-0107>

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The ethical imperative of ascertaining and respecting the wishes of the minimally conscious patient facing a life-or-death decision

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Individuals with three disorders of consciousness (DoCs) – coma, vegetative state (VS) and minimally conscious state (MCS) – and those with locked-in syndrome (LIS) have a significantly impaired ability to communicate by conventional means. Those in coma and VS are considered to be wholly unaware of their surroundings.¹ Individuals with LIS, and some people in MCS, however, are aware of their situation, and it is known that some of them wish to die.² Their physical disabilities make it impossible for them end their own lives: they are unable to administer an injection, pick up and swallow a tablet or use transport without assistance³ so, unlike their able-bodied counterparts, they have to rely on others' willingness to comply with their requests to be allowed to die. English law prohibits anyone from actively bringing about anyone else's death: the Suicide Act 1961 decriminalised suicide (s. 1), but intentionally encouraging or assisting someone else's suicide or attempted suicide continues to be a crime (s. 2(1)(a)). Since 1993, English courts have permitted the cessation of the artificial prolongation of lives of some people in VS, characterising this as an omission rather than a commission. A different approach has prevailed in cases where individuals in MCS or with LIS, or their next-of-kin, have pleaded for assistance in terminating their lives. Judges have expressed profound sympathy for the patients in such cases, but have consistently denied their requests, holding that, unless Parliament chooses to change the law on assisted suicide, the test must remain a person's best interests, which public policy deems to be served, *inter alia*, by the continuation of his or her life. This paper reviews some significant recent advances in neuroimaging techniques that appear, for some individuals, to

¹ See, eg, S Laureys, AM Owen, ND Schiff, 'Brain function in coma, vegetative state, and related disorders' (2004) *The Lancet Neurology* 3(9), 537–546; C Schnakers, J Giacino, S Laureys, 'Coma: Detecting signs of consciousness in severely brain injured patients recovering from coma' in JH Stone, M Blouin (eds), *International Encyclopedia of Rehabilitation* (2010); Royal College of Physicians, *Prolonged disorders of consciousness: National clinical guidelines*. (RCP: London, 2013).

² For a discussion of some English cases involving patients with LIS who have argued for their right to die see Claydon, L, 'Should there be a right to die with dignity in certain medical cases in the United Kingdom? Some reflections on the decision of the United Kingdom Supreme Court regarding the protection afforded by Article 8 of the European Convention for the Protection of Human Rights' [Citation to where it appears ELSEWHERE IN THIS YEARBOOK?????????](#)

³ In recent years a number of severely disabled English people have travelled to Dignitas in Switzerland where they have received assistance to end their lives.

differentiate more accurately than do established clinical techniques between those in MCS and those in VS, and which may enable some individuals who have been diagnosed as being in MCS or VS to give deliberate positive or negative answers to simple questions. Given English law's approach to end-of-life decisions for such individuals, these advances clearly have great legal and practical significance. This paper argues that, wherever possible, the wishes of those who are able to communicate only via neuroimaging should be sought, should be respected and, wherever practicable, should be acted upon. To do otherwise is to infringe the last vestige of autonomy of people who have already lost their dignity, their independence and, in some cases, their desire to live.

MCS was differentiated from VS in 2002.⁴ It will be the diagnosis if a patient is able to demonstrate purposeful behaviour, cry or smile responsively, or follow moving objects with their eyes.⁵ A patient will be considered to have recovered from MCS when he or she is able to attempt to use two simple objects appropriately, or to answer six simple questions correctly on two consecutive assessments.⁶ It is noteworthy that both sets of criteria involve patients' ability to exert control over one or more parts of their bodies: it was suggested that patients could answer questions via 'verbalization, writing, yes/no signals or use of augmentative communication devices'.⁷ It is a matter for concern that, although all these indicators inevitably show that such patients have, at least, a minimal level of awareness of themselves and their environment, there are no established and widely available tests that can detect such awareness in the absence of a physical manifestation of it. This means that there are some people who are conscious of their plight, yet who are unable to convey to their doctors and carers that this is the case, making it highly likely that they will be diagnosed as being in VS rather than in MCS.

Functional magnetic resonance imaging (fMRI) makes it possible to see which areas of a person's brain are the most active at a specified time. One fMRI study indicated that a patient

⁴ JT Giacino and others, 'The minimally conscious state: Definition and diagnostic criteria (2002) *Neurology* 58 (3), 349–353

⁵ C Schnakers, J Giacino, S Laureys, 'Coma: Detecting signs of consciousness in severely brain injured patients recovering from coma' in JH Stone, M Blouin (eds), *International Encyclopedia of Rehabilitation* (2010)

⁶ JT Giacino and others, 'The minimally conscious state: Definition and diagnostic criteria (2002) *Neurology* 58 (3), 349–353

⁷ JT Giacino and others, 'The minimally conscious state: Definition and diagnostic criteria (2002) *Neurology* 58 (3), 349–353 at p. 351

in MCS could experience emotions.⁸ A paradigm validated on healthy volunteers⁹ involved asking people to visualise either playing tennis or walking around their homes, since these thoughts involve increased activity in different parts of the brain. The same instructions were given to 17 patients who had been diagnosed as being in VS for less than six months, and two of them showed brain activity consistent with awareness of the task and an appropriate response to it.¹⁰ Within a year of the fMRI scan, both patients had begun to show behavioural changes that resulted in their diagnosis being changed to MCS.

The ability to identify responses in two different parts of the brain led to a larger-scale study involving 54 patients in MCS or VS.¹¹ Five patients, four of whom had been diagnosed as being in VS, showed brain activity similar to that of healthy individuals. The study then explored whether the same paradigm could be used for communication: individuals were asked some simple questions requiring ‘yes’ or ‘no’ answers, and instructed to visualise playing tennis if they wanted to answer ‘yes’, and to visualise walking around their homes if they wanted to answer ‘no’, or *vice versa*. All 16 healthy control subjects, and one patient who had been repeatedly diagnosed as being in VS – he was confirmed as being in permanent VS more than three years after he had been involved in a traffic accident – showed the ability to respond as requested. The patient was asked six simple autobiographical questions, such as ‘Do you have any brothers?’, and he used brain imagery to provide correct answers to five of them. He gave no response to the sixth question, for reasons that are unknown. The fMRI study was carried out at the Liège University Hospital, Belgium, where the patient was also repeatedly re-assessed using conventional means. He showed, inconsistently, some behaviours indicative of MCS, but remained completely unable to communicate with clinicians at his bedside. Neuroimaging appears to have been the only method by which this individual could indicate that he was aware, and that he was able to comprehend and respond to questions; if it had not been available, he would have continued to be regarded as oblivious to his condition and his surroundings.

⁸ T Bekinschtein and others. ‘Emotion processing in the minimally conscious state’ (2004) *J. Neurol. Neurosurg. Psychiatry* 75, 788

⁹ M Boly and others, ‘When thoughts become action: An fMRI paradigm to study volitional brain activity in non-communicative brain injured patients’ (2007) *Neuroimage* 36, 979–992

¹⁰ AM Owen and others, ‘Detecting awareness in the vegetative state’ (2006) *Science* 313, 1402; AM Owen, MR Coleman, ‘Functional Neuroimaging of the Vegetative State’ (2008) 9 *Nat. Rev. Neurosci.* 235–243

¹¹ MM Monti and others, ‘Willful Modulation of Brain Activity in Disorders of Consciousness’ (2010) *N. Engl. J. Med.* 362, 579–589

This visualisation paradigm was reported to have been used to enable a Canadian man who had been diagnosed as being in VS for 12 years to tell his doctors that he was not in pain.¹² There are constraints on this communication technique. It cannot, at least at present, be used to provide nuanced or conditional answers. However, it appears that it does provide a potential means of communicating with some people who are otherwise unable to make their wishes known at all. It is therefore submitted that it must be appropriate to use this technique as often as possible to ascertain how patients with DoCs wish to be treated.

It has been argued that the positive or negative responses obtained using fMRI cannot constitute informed consent, because there can be no discussion of any treatment options other than those initiated by the assessor.¹³ This is accepted but, at present, the views of patients whose DoCs render them unable to communicate by conventional means are not even sought. It must surely be preferable to offer them every possible opportunity to indicate their preferences regarding treatment and options – including, arguably, the fundamental issue of whether they wish to be allowed to die or to have their lives preserved as long as possible – even if their responses would not meet all the generally accepted requirements for legally valid informed consent. At the very least, the ability to give ‘yes’ or ‘no’ answers could be used to enable a patient to identify whom he or she wished to serve as *guardian ad litem*.¹⁴ It is difficult to see how it can be ethical not to attempt to ascertain someone’s wishes about the most important decision they will ever make.

The leading English case on the courts’ approach to patients with DoCs remains *Airedale NHS Trust v Bland*.¹⁵ By the time his case reached the House of Lords, which was then the highest court in the United Kingdom, Anthony Bland had been in PVS for over three-and-a-half years since being crushed at the Hillsborough football stadium disaster in April 1989. He was able to breathe unaided, but was kept alive via artificial nutrition and hydration (ANH). Brain scans had shown that his brain had largely degenerated. In the Court of Appeal, the

¹² F Walsh, ‘Vegetative patient Scott Routley says “I’m not in pain”’ (2012) BBC News. Online: <http://www.bbc.co.uk/news/health-20268044> (accessed 21/09/2014).

¹³ JJ Fins, ND Schiff. ‘In the Blink of the Mind’s Eye’ (2010) *Hastings Center Report* (May–June) 40(3), 21–23. This issue is explored further by C. Rödiger (2014) in her article entitled ‘Obtaining informed consent through use of brain-computer interfaces? Future perspectives in medical health care’ citation to where it appears in the *Year book*

¹⁴ C Rödiger, ‘Disorders of consciousness and decision making: Issues raised by the use of neuroscientific techniques in German Law’ in Ralf J Jox and others (eds), *Vegetative State – A Paradigmatic Problem of Modern Societies* (Lit Verlag, Münster, 2012)

¹⁵ [1993] A.C. 789, [1993] 2 W.L.R. 316

Master of the Rolls said: ‘The space which the brain should occupy is full of watery fluid’.¹⁶ It was therefore accepted as being beyond question that Anthony Bland had no awareness of himself, his surroundings or his situation, and that he could not feel any pain or discomfort. The health authority responsible for the care of Anthony Bland, with the support of his parents, applied to the High Court for a declaration that it would be lawful to withdraw ANH in order to allow him to die, in the words of the original request for a High Court declaration, ‘peacefully with the greatest dignity and the least pain, suffering and distress’. This decision was upheld by the Court of Appeal and the House of Lords. It was held that it was not in Anthony Bland’s best interests to have his life artificially prolonged, because he could not derive any benefit from living, and it was accepted that the near-complete degeneration of his brain meant that death by dehydration and starvation would not be distressing or painful for him. The courts drew a clear distinction between actively bringing about death, which would be unlawful, and discontinuing an intervention whose absence would allow the patient to die. In the House of Lords, Lord Keith of Kinkel (1993 AC 789 at 857) observed that:

The first point to make is that it is unlawful, so as to constitute both a tort and the crime of battery, to administer medical treatment to an adult, who is conscious and of sound mind, without his consent ... Such a person is completely at liberty to decline to undergo treatment, even if the result of his doing so will be that he will die. This extends to the situation where the person, in anticipation of his, through one cause or another, entering into a condition such as P.V.S., gives clear instructions that in such event he is not to be given medical care, including artificial feeding, designed to keep him alive.

In this case, it was impossible to know what Anthony Bland’s wishes would have been: as a 17-year-old football fan, excited at the prospect of seeing his team in an important Football Association semi-final match, he was most unlikely to have given the matter any thought either at the time he sustained his injuries or before.

The Mental Capacity Act 2005 (MCA) has put the ‘best interests’ test applied in *Bland* onto a statutory footing. Additionally, the MCA allows mentally competent¹⁷ individuals aged 18 or

¹⁶ [1993] 1 All ER 821 at 834

¹⁷ In *A Local Authority v E (by her litigation friend, the Official Solicitor) and others* [2012] EWHC 1639 (COP) the Court of Protection found that a 32 year old woman with extremely severe Anorexia Nervosa,

over¹⁸ to make advance decisions on issues including their medical treatment should they at some point in the future cease to be mentally competent.¹⁹ If an advance decision relates to refusing ‘life-sustaining treatment’ certain additional requirements must be satisfied.²⁰ For an individual who subsequently falls into MCS or VS the advance decision not only provides an opportunity to make treatment / end-of-life decision preferences known in advance, but also has the same force as a decision made by a mentally competent patient at the time. Under English law a mentally competent adult can refuse treatment, including life-sustaining treatment, even if others consider that treatment to be in the individual’s best interests. Similarly an advance decision can be made to refuse treatment, even life-sustaining treatment.²¹ In *X Primary Care Trust v XB (by the Official Solicitor as litigation friend) and another*²² an individual with motor neurone disease who was able to indicate agreement to a statement by moving his eyes to the right was held to have made a valid advance decision to refuse life-sustaining treatment.²³ Accordingly, the court held that his wishes should be followed.

Adult patients who are mentally competent and in a position to communicate their wishes will have the opportunity to refuse treatment at the time when decisions about treatment need to be made. Such patients may change their minds from any previously held view that they may have had. The MCA similarly provides an opportunity for individuals to vary or withdraw any advance decision that they have made.²⁴ The MCA also places the person holding the lasting power of attorney under a duty to seek the views of the individual who has made the advance decision.²⁵ It has hitherto been assumed that patients in MCS or VS are not

Alcohol Dependency Syndrome and borderline Emotionally Unstable Personality Disorder at the time of making her advance decisions was not mentally competent for the purposes of the Act.

¹⁸ This means that someone of Anthony Bland’s age would not be able to make an advance decision.

¹⁹ Advance decisions regarding medical treatment are governed by ss. 24 – 26 of the Act

²⁰ Advance decisions refusing life-sustaining treatment must be in writing, signed by or on behalf of the person making the advance decision, witnessed and must contain a statement from the patient that the advance decision is to apply even if life is at risk (ss. 25(6) and (7)).

²¹ By contrast, a patient cannot insist on a particular form of treatment, though a patient can request it. Similarly a patient by means of an advance decision can make known preferences as to future treatment, but cannot be assured that these wishes will necessarily be followed.

²² [2012] EWHC 1390 (Fam)

²³ In this case the life-sustaining treatment was an invasive ventilation device

²⁴ There are no specific formalities that must be observed unless the change is to refuse life-sustaining treatment in which case the requirements set out in ss.25(6) and (7) must be followed.

²⁵ The Office of the Public Guardian’s guide entitled *Lasting power of attorney for health and welfare under the heading general principles* states: ‘1. Your attorneys must assume that you can make your own decisions unless they establish that you cannot do so. 2. Your attorneys must help you to make as many of your own decisions as you can. They cannot treat you as unable to make the decision in question unless all practicable steps to help

able to express a view, but the work of Owen and Monti ²⁶ suggests that this assumption may not always be accurate. It is submitted that where advance decisions to refuse or request life-sustaining treatment have previously been made, clinicians should always explore the possibility of patients in MCS or VS being provided with the opportunity, if practicable, to confirm or deny their previously expressed decision. In seeking the patient's view, clinicians must remember the statutory assumption that 'A person must be assumed to have capacity unless it is established that he lacks capacity.'²⁷

Where a patient has not made a valid advance decision, the MCA specifies that decisions as to treatment must be made on the basis of the patient's best interests.²⁸ In determining best interests with regard to treatment, a court cannot require that a particular form of treatment is offered.²⁹ However, a court can refuse treatment in general, or any specific form of treatment if that is in the best interests of the patient.

The 'best interests' test is not necessarily satisfied by following accepted medical practice. It must be the best option for the patient in question.³⁰ Similarly the 'best interests' test does not mean that it can never be in the patient's best interests to withhold or withdraw life-sustaining treatment.³¹ The 'best interests' test, as it applies to decisions whether or not to refuse treatment, is a balancing act between the arguments for treatment and the arguments against treatment. Even where the treatment is life-sustaining, the question is not whether it is better

you to do so have been made without success.' (Office of the Public Guardian (2013), Lasting power of attorney for health and welfare, p2)

²⁶ See footnotes 8 and 9

²⁷ s.1(2) MCA. In *A Local Authority v E (by her litigation friend, the Official Solicitor) and others* [2012] EWHC 1639 (COP) Peter Jackson J held that this should be determined on the balance of probabilities [47]

²⁸ Guidance on interpreting best interests is provided in s.4 MCA.

²⁹ As Lady Hale DP stated in *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 [18] 'the case was not about a general power to order how the doctors should treat their patient. This Act is concerned with enabling the court to do for the patient what he could do for himself if of full capacity, but it goes no further. On an application under this Act, therefore, the court has no greater powers than the patient would have if he were of full capacity.' She noted with approval that the trial judge had said: 'A patient cannot order a doctor to give a particular form of treatment, although he may refuse it. The court's position is no different.'

³⁰ In *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 [24] Lady Hale DP approved the distinction between the Bolam test for medical negligence which sets out that following accepted medical practice cannot amount to negligence and the best interest test. Lady Hale approved the decision of the Court of Appeal in *Re S (Adult Patient: Sterilisation)* [2001] Fam 15, that there can logically only be one best option.

³¹ This line of argument was advanced by the Official Solicitor in *W (by her litigation friend, B) v M (by her litigation friend, the Official Solicitor) and others* [2011] EWHC 2443 [99] and rejected by Baker J [102].

to live or die, but whether it is better to have the full range of that treatment, some elements of it³² or no treatment at all.

In *W v M*³³ the patient, ‘M’, was in MCS. The judge noted that this was the first case in which the English courts had been called upon to determine whether or not it was in the best interests of a patient in MCS to refuse life-sustaining treatment. In analysing M’s best interests Baker J broke his judgment down into a number of themes: preservation of life,³⁴ M’s wishes and feelings,³⁵ pain,³⁶ enjoyment of life,³⁷ dignity,³⁸ and the wishes and feelings of family members and carers.³⁹ In relation to most, if not all, of these issues the voice of M, if she could have expressed her views, would have been informative and might have affected the final balance.

In his judgment Baker J quoted certain paragraphs from the Code of Practice that the Lord Chancellor, the head of the judiciary in England and Wales, had been required⁴⁰ to publish⁴¹:

All the factors in the best interests checklist should be considered, and in particular, the decision-maker should consider any statements that the person has previously made about their wishes and feelings about life-sustaining treatment. (para 5.32)

In setting out the requirements of working out a person’s ‘best interests’, section 4 of the Act puts the person who lacks capacity at the centre of the decision to be made. Even if they cannot make the decision, their wishes and feelings, beliefs and values should be taken fully into account – whether expressed in the past or now. (para 5.38)

³² For example, in *Sheffield Teaching Hospitals NHS Foundation Trust v TH and another* [2014] EWCOP 4 the court were initially asked to make decisions regarding refusing consent to withdrawal of two treatments: (1) antibiotic therapy and (2) withdrawal of nutrition and hydration. In *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 the court was asked to consider refusing consent to three treatments: (1) invasive support for circulatory problems, (2) renal replacement therapy and (3) cardiopulmonary resuscitation. In both cases the court was free to decide that the patients should receive some, all or none of the treatments in question.

³³ [2011] EWHC 2443

³⁴ *Ibid.* Explored in paragraphs [220] – [222]

³⁵ *Ibid.* [223] – [230]

³⁶ *Ibid.* [231] – [233]

³⁷ *Ibid.* [233] – [237]

³⁸ *Ibid.* [240] – [241]

³⁹ *Ibid.* [242]

⁴⁰ This requirement is contained in ss. 42 and 43 MCA,

⁴¹ Quoted in *W by her litigation friend, B) v M (by her litigation friend, the Official Solicitor) and others* [2011] EWHC 2443 [224]

M had been unable to communicate in any way which could be understood by those around her since falling into a coma as a result of viral encephalitis for more than eight years prior to the trial. She had emerged from the coma and been diagnosed as being in VS. Subsequently she had been re-diagnosed as in MCS, though the level of her MCS was disputed by the expert witnesses called in her case.⁴² There was also dispute as to the quality of her life and whether or not she was in pain. Reassuringly, great efforts were undertaken to try to determine these issues. Evidence was provided by members of M's family, 10 staff who worked at the care home at which M lived and two medical experts. Additionally, the court was provided with results using the Sensory Modality Assessment and Rehabilitation Technique (SMART) and the Wessex Head Injury Matrix (WHIM). Despite these efforts, no clear consensus emerged as to whether the witnesses felt that M had any appreciable quality of life or whether she was in pain. If through fMRI it had been possible to identify her current views about whether she was in pain, whether she enjoyed her life and whether she wanted to continue to receive life-sustaining treatment then a much better-informed assessment of her best interests could have been made.

Despite uncontested evidence from her family that M had on more than one occasion made it clear that, in circumstances such as those which now prevailed, she would not wish to be kept alive, the court gave great weight to the fact that she was sensate and aware, and could communicate in a very limited way. This meant that she was 'recognisably alive in a way that a patient in VS is not'⁴³, and Baker J therefore ruled that her ANH must continue: 'In my judgment, the importance of preserving life is the decisive factor in this case.'⁴⁴

This stark contrast in the courts' approach towards patients in VS, such as Anthony Bland, and those, like M, who retain some level of awareness is worrying. The position in English law seems to be that, if a person is apparently wholly unaware of his situation and has no hope of recovery, his life can lawfully be ended by withdrawing the clinical intervention by which it is being artificially prolonged. By the time of the three judicial decisions that it would be lawful to allow Anthony Bland to die, he was regarded as having no thoughts or

⁴² One expert viewed M as being towards the higher end of the spectrum of MCS states; another expert viewed her as at the lower end, closer to VS.

⁴³ [2011] EWHC 2443 [221]

⁴⁴ Ibid [249]

feelings, and this lack of awareness was a significant factor in the courts' reasoning. If, however, the patient has any level of understanding of her helplessness, lack of dignity and extremely poor prospects of any significant recovery – and very probably, by the account of those closest to her, finds her situation intolerable – her life may be artificially prolonged until she develops a clinical condition that will end it.

This divergence in approach highlights the profound significance of a determination as to whether an individual is in VS or MCS. It is therefore of great concern that misdiagnosis is 'a significant problem'⁴⁵ and some studies suggest that around forty per cent of people diagnosed as being in VS may in fact be in MCS.⁴⁶ The fact that four individuals diagnosed with VS were able to modulate their brain activity in the same way as healthy control subjects⁴⁷ indicates the importance of using sensitive neuroimaging techniques, rather than merely employing traditional clinical observation and structured assessment tools, to determine whether a person has any degree of consciousness. It seems unlikely that the fMRI results would give false positives; there is a much higher risk that, even with the latest technologies, there will continue to be some people whom everyone regards as being insensate but who are actually aware of what is happening to them – and who, perhaps, hear others discussing whether they should be allowed to live or die.

M was originally diagnosed as being in VS and only when further tests were undertaken was she found to be in MCS. It is at least arguable that, from her perspective, the correction of the diagnosis had dire consequences; had she continued to be regarded as being in VS, the court's decision about the prolongation of her life may have been different. In *W v M* the court stated that in all cases of VS or MCS there should be a SMART assessment (or equivalent) and that in cases of MCS there should also be a WHIM assessment or equivalent.⁴⁸ However, in the

⁴⁵ Royal College of Physicians, Prolonged disorders of consciousness: National clinical guidelines. (RCP: London, 2013), pp 14, 16.

⁴⁶ K Andrews and others, 'Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit' (1996) *BMJ* 313, 13–16

⁴⁷ MM Monti and others, 'Willful Modulation of Brain Activity in Disorders of Consciousness' (2010) *N. Engl. J. Med.* 362, 579-589

⁴⁸ This is called for by Baker J in *W (by her litigation friend, B) v M (by her litigation friend, the Official Solicitor) and others* [2011] EWHC 2443 [259] and followed by Hayden J in *Sheffield Teaching Hospitals NHS Foundation Trust v TH and another* [2014] EWCOP 4 [4]

light of the work of Owen, Monti⁴⁹ and others⁵⁰, it is argued that the need for fMRI assessment of those diagnosed as being in VS should be investigated and, if the findings are shown to be robust and if it is practicable, such further testing should be required. The use of fMRI to ascertain whether patients are accurately identified as being in VS may be crucial, not just for families seeking to avoid the withdrawal of life-sustaining treatment from their loved ones, but also in order to find out more about the current quality of life, experience of pain and discomfort, and life / death preferences of those receiving life-sustaining treatment.

In 2014 in *Sheffield v TH*⁵¹ the Court of Protection was again called upon to determine whether life-sustaining treatment for a patient should be continued. The patient, who had not made an advance decision, was at the lower end of the MCS spectrum.⁵² The patient's friends gave evidence that he would find his situation intolerable, and his ex-wife commented:

All I can say is that I believe with all my body and soul that TH would find the situation he was in a living hell, and if we cared anything for him, we would let him go and find peace.⁵³

The judge himself acknowledged the significance of the patient's previously expressed views:

He may not have prepared a document that complies with the criteria of section 24 [of the MCA], giving advance directions to refuse treatment but he has in so many oblique and tangential ways over so many years communicated his views so uncompromisingly and indeed bluntly that none of his friends are left in any doubt what he would want in his present situation.'⁵⁴

Nonetheless, the judge did not order that it was in the patient's best interests for life-sustaining treatment to be refused; instead, he adjourned determination of this issue until

⁴⁹ Footnotes 8 and 9.

⁵⁰ For a discussion of other work in this area see C. Rödiger (2014) 'Obtaining informed consent through use of brain-computer interfaces? Future perspectives in medical health care' citation to where it appears in the *Yearbook*

⁵¹ [2014] EWCOP 4

⁵² He had a reduced Glasgow coma score of 3 out of 15 – the lowest possible score, indicative of a very severe depression of consciousness. [9]

⁵³ [2014] EWCOP 4 [45]

⁵⁴ *Ibid* [53]

assessment of TH's general awareness, responsiveness and capacity to experience pain had been established.

The issue of end-of-life decisions for those in MCS obviously overlaps with the question of assisted suicide explored elsewhere in this Yearbook.⁵⁵ Both the English courts and the European Court of Human Rights have accepted that withdrawing life-sustaining treatment may not infringe the right to life enshrined in Article 2 of the European Convention on Human Rights.⁵⁶ The question of whether or not continuing life-sustaining treatment where it is 'futile, overly burdensome to the patient or where there is no prospect of recovery'⁵⁷ amounts to a breach of the right not to be subjected to torture, or inhuman or degrading treatment under Article 3, or to a breach of the right to private and family life afforded by Article 8, has not been tested. In *M*'s case consideration was given to the question of Article 3, and the case of *Herczegfalny v Austria* was employed to argue that 'as a general rule, a measure which is a therapeutic necessity cannot be regarded as inhuman or degrading.'⁵⁸

However, this assumes that life-sustaining treatment for someone who does not want it and who feels that they have has no appreciable quality of life can amount to a therapeutic necessity. In *W v M*, the court's attention was drawn to the comment of Butler-Sloss P in

⁵⁵ Claydon, L, 'Should there be a right to die with dignity in certain medical cases in the United Kingdom? Some reflections on the decision of the United Kingdom Supreme Court regarding the protection afforded by Article 8 of the European Convention for the Protection of Human Rights' ELSEWHERE IN THIS YEARBOOK?????????

⁵⁶ See for example *Glass v United Kingdom* (2004) 39 EHRR 341 on the validity of a Do Not Resuscitate order and *NHS Trust A v M* [2001] Fam 348 where the treatment would be futile.

⁵⁷ These words are taken from the MCA Code which states that:

5.31 All reasonable steps which are in the person's best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the person's death. The decision-maker must make a decision based on the best interests of the person who lacks capacity. They must not be motivated by a desire to bring about the person's death for whatever reason, even if this is from a sense of compassion. Healthcare and social care staff should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment.

Whilst the Code indicates that where treatment is 'futile, overly burdensome to the patient or where there is no prospect of recovery' life-sustaining treatment may be refused, it does not say that it must be refused. Therefore there could be situations where a court decides notwithstanding the fact that one or more of the factors applies treatment should not be refused. Further difficulties arise in determining what each of the three concepts mean in practical terms.

⁵⁸ (1992) 15 EHRR 437 at para 82, quoted in *W (by her litigation friend, B) v M (by her litigation friend, the Official Solicitor) and others* [2011] EWHC 2443 [92]

*NHS Trust A v M*⁵⁹ that, as an insensate patient has no feelings and no comprehension of the treatment, treatment of such a patient cannot breach Article 3. However, as Baker J noted, Butler-Sloss P's argument does not necessarily apply in a case involving a patient in MCS⁶⁰. Accordingly an argument exists that treatment to which a patient in MCS has not consented and which is not 'therapeutic'⁶¹ could be challenged using Article 3. The assisted suicide cases⁶² have established that Article 8 is engaged in cases involving decisions as to the end of life. In those cases, the need for a positive act to assist suicide, which is a criminal offence, has been used to argue that such a restriction on the right to respect for one's private and family life is proportionate. This argument, however, does not apply to those who are seeking merely to refuse the continued provision of treatment that artificially prolongs life. In English law, adults who are mentally capable and able to communicate their wishes can refuse such treatment, and such refusals must be respected, but those who are not able to communicate their views are denied that opportunity. This raises the possibility of using Article 14 of the Convention, which prohibits discrimination on a range of grounds, including disability, in the application of the other substantive rights, in conjunction with either Article 3 or Article 8. In the future, a better understanding of whether people with DoCs experience pain may also inform thinking about the methods by which lives are ended, and this may necessitate a review of the current practice of, for example, withdrawing ANH from such patients.

In conclusion the fMRI techniques being developed to better differentiate between patients in MCS and VS and the developments which enable some of those in MCS to communicate, at least in a binary way, have important potential uses for those making treatment and end-of-life decisions for people in MCS. Assuming that the science is proven robust, fMRI technology should be harnessed to the greatest practicable extent to ascertain the wishes of those in MCS. The fundamental ethical principle of respect for patients' autonomy and the importance of individuals' views when their best interests are being determined mean that

⁵⁹ *NHS Trust A v M*, *NHS Trust B v H*. [2001] 1 All E.R. 801

⁶⁰ The case was decided before MCS was identified as a distinct clinical condition.

⁶¹ 'Therapeutic' is defined in the online Oxford English Dictionary (accessed 21/09/2014) as meaning: 'concerned with the remedial treatment of disease; the art of healing'. This term it is argued does not cover keeping someone alive in circumstances where there is no realistic hope of curing their condition.

⁶² Claydon, L, 'Should there be a right to die with dignity in certain medical cases in the United Kingdom? Some reflections on the decision of the United Kingdom Supreme Court regarding the protection afforded by Article 8 of the European Convention for the Protection of Human Rights' [Citation to where this appears in the Yearbook](#)

any such wishes must be respected to the greatest extent that the law allows: it is, after all, each patient's life or death that is at stake.