

End-of-life Decision-making for People in a Minimally Conscious State: A Review of the Application of the Mental Capacity Act 2005

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Abstract

The last 15 years has seen clarification of the terminology used to describe prolonged disorders of consciousness within the United Kingdom leading to the emergence of a new diagnosis – minimally conscious state (MCS) in 2002. MCS is distinct from vegetative states, in that a person demonstrates wakefulness with some degree of minimal awareness. The Mental Capacity Act (MCA) 2005 in England and Wales provides a legal framework for assessing an individuals’ capacity to make decisions for themselves. The Act also authorizes others to make decisions on behalf of an individual who is assessed as lacking capacity in their best interests. The Act has an accompanying Code of Practice which provides guidance and a best interests “test” to be applied when assessing best interests. Since the advent of the Act, approximately two cases each year go to the Court of Protection for final decisions regarding end-of-life care in people in an MCS. Currently, any decision involving the withdrawal of clinically assisted nutrition and hydration (CANH) for people in an MCS must be referred to the court. In each case, the courts analyze the application of the Act which has become central in the court’s decision-making process, particularly when assessing best interests. This article provides an overview of key MCA sections applied in such end-of-life MCS cases and reviews seminal cases elucidating how the Act has been applied. It further describes the evolution of how courts have interpreted the doctrine of best interests when considering withholding or withdrawing CANH and other life-sustaining treatments.

Keywords: Clinically assisted nutrition, hydration, Mental Capacity Act 2005, minimally conscious state

INTRODUCTION

In England and Wales, a new statute, the Mental Capacity Act 2005 (MCA), was introduced to provide a framework for the assessment of capacity of individuals to make decisions for themselves. It also provides numerous safeguards for those assessed as lacking capacity to make important decisions. The MCA was enacted in 2007 and case law has developed through judgments emanating from the Court of Protection which hears initial cases around the MCA. Disputed cases have reached the highest court in the land, the Supreme Court which, being the final court of appeal, is the final arbiter in these matters within the United Kingdom (UK).

The primary focus of the MCA is around treatment and welfare decision-making. All aspects of medical treatment can be subsumed under the MCA, and it is often applicable to end-of-life care for many. Needless to say, some end-of-life scenarios are so complex and unique that disputes arising

have needed to be decided by the courts. Since the inception of the MCA, there have been cases around end-of-life care and those diagnosed as being in a minimally conscious state (MCS) having been decided by the Court of Protection. This article looks at the evolution of these cases and analyzes seminal cases since 2007 to help understand how the MCA has been applied to the overall conclusions of the courts. In doing so, this will enable the reader to develop an understanding of jurisprudence in this specialist area of end-of-life care and how the MCA is intrinsic to these decisions.

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THE MENTAL CAPACITY ACT 2005

The MCA applies to those aged 16 years and over. Its main functions are to preserve individual autonomy and safeguard those who lack capacity. It also serves to protect and empower those making decisions on behalf of people who lack capacity. These include health- and social-care professionals and relatives. An MCA Code of Practice^[1] provides practical guidance and examples of best practice.

When a case is assessed by the Court of Protection, it will scrutinize the application of the MCA. In all cases, they will sequentially analyze the effect of key sections of the MCA [Box 1]. For the cases described below, Sections 1–3 will have been applied such that it can be taken as granted that the person involved unequivocally lacks capacity to make treatment decisions. The emphasis in the cases described is on assessing the best interests of the person for the treatment options and it is that which will be concentrated on. In weighing and balancing various best interests options, the courts will apply a structured checklist or best interests “test” in arriving at their conclusions [Box 1 – Section 4].

Other key sections of the MCA that are routinely considered are given below.

Section 9: Lasting powers of attorney

A lasting power of attorney (LPA) is a legal document that lets a person (“the donor”) appoint one or more people (“attorneys”) to make decisions on their behalf if they become unable to do so. There are two types of LPA: (1) health and welfare and (2) property and financial affairs. If a health and welfare LPA is in place, the attorney has the power to make decisions about medical care and life-sustaining treatment. There has been increasing uptake of LPAs in the recent years with more than 2 million having been registered by the end of 2016.^[2]

Section 15: Power to make declarations

This section contains the powers the Court of Protection has to make declarations as to the capacity of a person to make a specific decision and the lawfulness of any act done, or proposed to be done, to the person.

Sections 24–26: Advance decisions to refuse treatment

The MCA covers advance decisions to refuse treatments (ADRTs) (Section 24), their validity and applicability (Section 25), and effect (Section 26). An ADRT gives a person the right to make a decision to refuse treatment(s) in advance even if it results in their death. The importance of an ADRT is that if one exists and is valid and applicable to the clinical situation, then it carries the same weight as a decision made by that person with capacity, and so, a best interests decision would not apply (however, in the cases described below, even if a valid ADRT is in place, the case still needs to be referred to the Court of Protection). The uptake of ADRTs is still very low with rates in England estimated to be about 4% and Wales about 2%.^[3]

Sections 35–41: Independent mental capacity advocate service

This service provides incapacitated vulnerable people support to make decisions about “serious medical treatment” (which

includes providing, withholding, or stopping treatment) who have no family or friends to consult about such decisions. An independent mental capacity advocate will be instructed to represent an incapacitated person’s views to those who are assessing their best interests.

LITIGATION FRIEND

Where a person lacks litigation capacity to engage in court proceedings, they will need a litigation friend to be appointed who can conduct legal proceedings on their behalf. The litigation friend can be a relative, friend, advocate, or the official solicitor (litigation friend of “last resort” when no one else is willing or suitable to act).

VEGETATIVE STATE CASE LAW IN THE UNITED KINGDOM

In the UK, the national clinical guidelines issued for prolonged disorders of consciousness recommended that the term persistent or permanent vegetative state (PVS) should no longer be used and replaced by “vegetative state” (VS).^[4] Before the MCA, there was established case law around the withdrawal and withholding of clinically assisted nutrition and hydration (CANH) for patients confirmed to be in a VS. The seminal case was a House of Lords judgment (this being the highest court in the land before the Supreme Court replacing it in 2009) in *Airedale NHS Trust v Bland*.^[5] The case involved a young man called Anthony Bland who was a soccer supporter injured in the 1989 Hillsborough Stadium disaster. He incurred severe brain damage which left him in a confirmed VS. Due to this, the hospital with the support of his parents applied to the courts for an order to withdraw life-prolonging treatment including CANH. A core theme was that on-going treatment would, in medical terms, be futile due to there being no prospect of recovery and hence was not in the best interests of the patient.

The judgment concluded that it was lawful to discontinue all life-sustaining treatment which included termination of ventilation and CANH and an order was made to this effect. Mr. Bland was the first person in English legal history to be allowed to die through withdrawal of life-prolonging treatment including CANH and artificial ventilation (This judgment included consideration of similar end-of-life cases from the USA, e.g., *In re Quinlan*;^[6] *Superintendent of Belchertown State School v Saikewicz*^[7]). Since this judgment, it has been mandatory to seek judicial approval for the withholding or withdrawal of CANH to all people in a VS (and has been formalized through guidance within the MCA Code of Practice for those in a VS and by a Court of Protection Practice Direction^[8] for those in a VS or MCS).

MINIMALLY CONSCIOUS STATES

An MCS is one of the three prolonged disorders of consciousness along with coma and VS. The diagnostic criteria for MCS were developed in 2002^[9] and the first mention of MCS in court was in the same year.^[10] The diagnostic criteria

are more complex to apply than for VS due to it being an umbrella term for a broad spectrum of responsiveness – it can range from those with a few nonreflex movements to others who show some emotional responses, e.g., smiling, crying, laughing, or can verbalize or use objects, e.g., hairbrush in a consistent or meaningful manner.^[11] It is because of this diagnostic complexity that case law has evolved around the emotive issue of the withdrawal or withholding of CANH for those in an MCS.

The following describes key judgments concerning MCS and end-of-life care since the MCA came into effect and elucidates the complexities and intricacies contained therein.

THE MENTAL CAPACITY ACT AND CASES OF PEOPLE IN A MINIMALLY CONSCIOUS STATE

W v M and Ors (2011)

This was the first time in England that a court was asked to authorize the withdrawal of CANH and to withhold all life-sustaining treatment from a patient in an MCS. The case placed particular significance on the importance of differentiating between a VS and an MCS. It involved a 52-year-old female in whom viral encephalitis 9 years earlier had left her with permanent and extensive brain damage. On emerging from the initial coma, she was diagnosed as being in a VS but later was changed to one of an MCS. M was sensate, aware of her environment, could respond to people and music albeit in a limited way, and could communicate about her needs.

In applying Section 4 MCA, the court concluded that it was not in the best interests of the patient to authorize the withdrawal of life-sustaining treatment including CANH. The court scrutinized many important factors, and while preservation of life was the decisive factor, it emphasized the importance of a person's past and present wishes and feelings as part of the best interests assessment. This assessment adopted a balance sheet approach (first articulated in *Re A*^[12]) – weighing the advantages of continuing with CANH against the advantages of withdrawing CANH. While the court concluded that CANH should not be withdrawn in this case, it opined that judgments concerning future treatment options, e.g., antibiotic use, should be left to the treating clinicians because it was impossible to ascertain what would be in M's best interests for specific treatments at specific times in the future.

The judgment made observations to assist future applications for the withdrawal of CANH. It noted that any decision to withhold or withdraw CANH from a person in a VS/MCS must be referred to the Court of Protection. The judgment also noted that misdiagnosis may occur (it had previously opined that there had been older cases where patients having been diagnosed as being in a VS were probably in an MCS). Because misdiagnosis may occur, the judgment stated that in future, no application should be made for an order authorizing withdrawal of CANH from a patient in a VS/MCS unless certain assessments had been undertaken [Box 2].

The need for “rigorous evidential analysis” and the “absolute necessity for a structured assessment to have occurred” before any court application being considered was subsequently emphasized in *St. George's Healthcare NHS Trust v P and Q*.^[13] This was emphasized, whilst acknowledging the inherent complexities of such cases, in an effort to produce more diagnostic certainty as the judge commented, he was aware of rates of misdiagnosis of around 40% for people in a VS actually being in an MCS.

An NHS Trust v L and Ors (2012)^[14]

In this case, the court made declarations that it was lawful to withhold life-sustaining treatment including cardiopulmonary resuscitation (CPR) and invasive treatments such as ventilation and intubation in the event of a further serious medical deterioration. In doing so, the judgment threw up issues around diagnostic uncertainty and resource issues in providing such care.

The patient, Mr. L a 55-year-old man, had suffered severe hypoxic brain damage following a cardiac arrest. At the time of going to court, he was diagnosed as being in a VS; however, as court proceedings progressed, there was a possibility that he was at the lower end of the MCS spectrum. In contrast to *W v M*^[15] where all parties were in agreement that withdrawal of life-sustaining treatment was in the best interests of the patient, in this case, the family held the view that Mr. L was aware of himself and his environment and as a Muslim would have wanted all possible life-sustaining treatment to be continued. Hence, they avidly opposed the treating hospital's position. An independent expert instructed by the official solicitor on behalf of Mr. L supported the position of the hospital that active CPR and/or similar treatment for a serious deterioration in his condition would not be in Mr. L's best interests.

An interesting aspect of this case was that as there were no doctors identified who would provide the relevant life-sustaining treatment at issue, the judge opined that there were therefore no actual treatment options for the Court of Protection to make a declaration about. Applications of this nature made under the MCA must specifically address what treatment options are available and not merely theoretically available. Courts cannot enforce a doctor to provide treatment contrary to their professional clinical judgment. In light of this, Section 4 MCA was applied and the balancing exercise contained therein looking at factors pointing toward and against the use of CPR. Having weighed the competing factors, the judge concluded “the balance comes down firmly against the provision of active resuscitation and/or other similar treatment” and granted the Trust's application. The judge eloquently added that “Harsh though it may sound...to take the opposite course would indeed be...to prolong Mr. L's death and not to prolong, in any meaningful way, his life.”

Aintree University Hospitals NHS Foundation Trust v James (2013)^[16]

This was the first MCS case to come before the Supreme Court under the MCA and provided clarification regarding the approach to assessing best interests in such cases. It analyzed

Chapter 5 of the MCA Code of Practice which explains what the MCA means by acting in someone's best interests and sets out a checklist or "test" for establishing what is in someone's best interests [Box 1]. Paragraphs 5.29 – 5.36 of the Code provides explicit guidance as to how someone's best interests should be assessed when making decisions about life-sustaining treatment. The judgment in particular drew on Paragraph 5.31 [Box 3].

Mr. James, a 68-year-old man, was admitted to hospital in May 2012 for constipation of his stoma. This problem was resolved, but he then acquired an infection which was complicated by chronic obstructive pulmonary disease, acute kidney injury, and persistent hypotension. His condition deteriorated, requiring transfer to the critical care unit where he remained dependent on artificial ventilation, nutrition, and hydration. There were marked fluctuations in his presentation, and at times, he was able to track people with his eyes, recognize and smile at his family, and turn pages of a newspaper and mouth what appeared to be words. However, there was no clinical improvement, and until his death in December 2012, Mr. James' condition deteriorated. It was agreed by his treating clinicians that Mr. James met the criteria for an MCS. They felt that prospects of recovery were extremely low and that further invasive treatments would not be in his best interests. His family remained hopeful that although he would never have the same quality of life as previously, he may still be able to gain enjoyment from seeing his family and close friends. They did not agree with treatment being withheld, and despite the best interests meeting to discuss the issue, a consensus could not be reached.

The hospital applied to the Court of Protection seeking declarations including that it would be in his best interests for four specified treatments to be withheld in the event of clinical deterioration. These treatments included invasive support for circulatory problems, renal replacement therapy, CPR, and intravenous antibiotics for further infectious complications (although the latter was not pursued by the trust). Treating clinicians argued such treatments would be "futile and overly burdensome, with no prospect of recovery," but the judge was not persuaded and felt unable to make the declarations sought. The case was referred to the court of appeal and then, posthumously, to the Supreme Court.

The Supreme Court concluded the Court of Protection's decision had been a correct one. They agreed that the treatments in question could not be described as futile as there was evidence that they had provided some benefit in the past and it was not the case that they were unable to return Mr. James "to a quality of life that was worth living." Instead, they supported the judge's interpretation that recovery meant "resumption of a quality of life that Mr. James would regard as worthwhile." There was evidence to suggest that he continued to gain pleasure from seeing his family and friends and therefore had a measurable quality of life. Although it was acknowledged that the treatments were burdensome, the Supreme Court concurred

that Mr. James may have been able to recover in the sense that although he would never return to full health, he could regain a quality of life that he himself would consider worthwhile. The Supreme Court argued that "it is not for others to say that a life which the patient would regard as worthwhile is not worth living." The judgment continues to provide salient guidance on the assessment of best interests applied in subsequent MCS case law [Box 4].

Sheffield Teaching Hospitals NHS Foundation Trust v TH and Anor (2014)^[17]

The judgment, in this case, involving a 52-year-old man and the potential for withdrawal of CANH and active antibiotic treatment, reflected the decision in *Aintree*, reiterating the importance of patient's own views when constructing a balance sheet and coming to decisions about best interests. As in the case of *W v M*,^[15] and applying recommendations from it, the judge in this case emphasized the importance of separating the diagnosis of MCS from that of VS. He adjourned the case so that Sensory Modality Assessment and Rehabilitation Technique/Wessex Head Injury Matrix (SMART/WHIM) assessments could be completed to determine the level of MCS.

The judgment elucidated two important issues. First, it emphasized the vital importance of seeking and establishing the patients' views, wishes, and feelings on the decision at hand and how this closely involves evidence from family and friends to ascertain this where possible. The judge eloquently summed this up as "... whatever the ultimate weight to be given to TH's views it is important to be rigorous and scrupulous in seeking them out. In due course, the clarity, cogency, and force that they are found to have will have a direct impact on the weight they are to be given. "Wishes" and "best interests" should never be conflated; they are entirely separate matters which may ultimately weigh on different sides of the balance sheet." (A best interests balance sheet is an "aide memoir of key factors and how they match up against each other" to enable a route to judgment rather than a substitution for the judgment itself – *B v D*^[18]).

Second, there was analysis of ADRTs in MCS cases. Albeit proven not to be in place in this case had there been a valid and applicable ADRT proposed in this clinical scenario "the decision has effect as if he had made it and had had capacity to make it" (s26 (1)(b)).

County Durham and Darlington NHS Foundation Trust v PP and Ors (2014)^[19]

This case involved an 85-year-old woman, P, who had a complex medical history. On admission to hospital, her diagnoses included atrial fibrillation, vascular dementia, and possible Alzheimer's dementia with diminished consciousness, ischemic encephalopathy, and cerebrovascular disease. She had previously had a cerebrovascular accident, and during the admission, she probably had a further cerebrovascular event. She made no eye contact, appeared unconscious, and was unable to communicate or respond to commands. One treating doctor opined that P was considered as being "somewhere on

the spectrum between the VS and an extremely low position of the minimally conscious/minimally responsive state.” It was felt that P had entered a terminal phase of her life which was evocatively described as “pre-terminal hibernation” and that P was extremely unlikely to make progress along the MCS spectrum before death supervened. Despite the by now established jurisprudence, and seemingly some diagnostic uncertainty, the judgment made no mention of consideration for SMART/WHIM assessments. The court granted declarations sought by the hospital to continue CANH via subcutaneous injection but not to provide CANH by a percutaneous endoscopic gastrostomy (PEG) tube or via an alternative artificial feeding regimen, e.g., nasogastric tube feeding, and not to resuscitate in the event of a cardiac or respiratory arrest.

The judgment specifically mentioned the provisions of the MCA must be interpreted with regard to the Human Rights Act 1998 (as the European Convention on Human Rights is enacted in the UK). In this case, as is the case for all such MCS cases, the decisions being made did engage her article 8 rights the right to respect for private and family life (for further exposition of article 8 rights in clinical care see Curtice^[20]).

M and Mrs. N v Bury Clinical Commissioning Group (2015)^[21]

This was the first case in which the Court of Protection allowed CANH withdrawal from a person in an MCS. It concerned Mrs. N a 68-year-old woman with profound physical and cognitive impairment resulting from advanced multiple sclerosis. Her condition, including dementia and quadriplegia, was described as “remorselessly progressive” with a prognosis of around 3–5 years. She had been receiving CANH via a PEG tube for 7 years. The application was brought by Mrs. N’s daughter M, who argued that continuing with CANH would not be acting in her mother’s best interests. She felt that her mother was in an “intolerable” situation and “no longer remained alive in any sentient sense.” Evidence provided by Mrs. N’s family left the judge “in little doubt” that Mrs. N’s wishes would have been to discontinue her treatment. The strength of this evidence led to the official solicitor reversing his position as he felt that it would be wrong “to continue to oppose the application” and hence in the end none of the parties involved opposed the application made.

Expert evidence was given by three medical practitioners, all of whom had been involved in establishing the Prolonged Disorders of Consciousness National Clinical Guidelines,^[4] which aimed to provide clarity and consistency regarding the diagnosis and management of patients in a VS/MCS (the reader is heartily advised to read this judgment for an excellent contemporary review of VS/MCS diagnostic criteria). There was disagreement of opinion between these clinicians as to whether the term MCS could be applied to Mrs. N. It was argued that the term MCS had generally been attached to cases of “sudden-onset severe brain injury from whatever cause” and the practical purpose of evaluating a patient’s conscious level in these cases was to establish their potential for rehabilitation. As this is not the case for an individual at

the end stages of a progressive neurological condition such as MS who has impaired levels of arousal and interaction, two of the doctors had misgivings about using the term MCS. This was disputed by the third clinician who argued that both VS and MCS were “terms devised to be applied to patients with prolonged disorders of consciousness, irrespective of etiology.” All three doctors accepted that the Prolonged Disorders of Consciousness guidance did not exclude end-stage dementia or other progressive neurodegenerative disorders from the definition. Furthermore, completion of a SMART assessment had established that Mrs. N was reliably able to “fix and track” objects with her eyes, which precluded a diagnosis of VS. It was agreed the clinical findings established that Mrs. N was “at a low level of MCS.” The judge spent time elucidating the diagnosis because a VS diagnosis would have precluded a formal best interests assessment because of the Bland judgment.

The judge stressed that, although withdrawal of treatment would lead to Mrs. N’s death, the case was not about Mrs. N’s right to die but was instead concerned with balancing the principle that places sanctity of life above all things with an individual’s right to self-determination and made reference to Lord Justice Hoffman’s judgment in the case of Bland “...the law must reassure people that the courts do have full respect for life, but that they do not pursue the principle to the point at which it has become almost empty of any real content and when it involves the sacrifice of other values such as human dignity and freedom of choice.” The judge granted declarations that it was lawful and in Mrs. N’s best interests for her to receive CANH while urgent arrangements were put in place for her to be transferred to an appropriate care home/hospice and for a care plan to be drawn up for the withdrawal of CANH. This affirmed that in this case, “respect for Mrs. N’s dignity and human freedom overwhelms further prolongation of life.” The judge was completely satisfied there was no prospect of Mrs. N having a life “she would consider meaningful, worthwhile, or dignified.” He concluded that it would have been “disrespectful to Mrs. N to preserve her further in a manner I think she would regard as grotesque.”

The judge made clear the focus was on Mrs. N’s right to live her life at the end of her days in the way she would have wished. He had acquired an in-depth life story gleaned from her daughter, son, and ex-husband to formulate the likely views and attitudes of Mrs. N. The judge placed great emphasis on the importance of the wishes and feelings of an incapacitated adult being communicated to the court via family or friends with “cogency and authenticity” being afforded “no less significance” than those of a capacitous adult. The judge provided further eloquent discourse on this and the best interests assessment [Box 5].

Briggs v Briggs and Ors (2016)^[22]

This case, like Bury, focused on the decision as to whether CANH should be continued or withdrawn for an MCS patient. However, unlike Bury, in this case, there was disagreement between the parties involved. The judge was asked to decide

between a dichotomy of treatment plans: (1) that Mr. Briggs was moved to a rehabilitation unit for further assessment and treatment, including CANH, with potential for improvement or (2) that he was moved to a hospice where CANH was discontinued and to then receive palliative care until his death.

Mr. Briggs was a Gulf War veteran, and after active service, he joined the police force. He was involved in a road traffic collision in July 2015. He suffered a traumatic brain injury and after several months was diagnosed as being in an MCS being confirmed by SMART assessments. In spring 2016, he was determined to be in a middle ground between “MCS minus (the closest to a VS) and MCS plus (nearest to emergence from MCS)” but that there had been a small improvement since an initial assessment.

Around 17 months after his accident, the treating team opined that Mr. Briggs should be transferred to a rehabilitation facility where his progress could be “monitored and promoted” for at least 6 months. A realistic best case scenario was propounded that Mr. Briggs could be happy, experience pleasure, be able to make simple decisions, and not be distressed or depressed and that his troublesome paroxysmal sympathetic hyperactivity, dystonia, and contractures could improve. His wife and family were of the opinion that CANH should be withdrawn and he is transferred to a hospice where he would receive palliative care, enabling him to pass away peacefully. In doing so, they proffered several anecdotes illustrating Mr. Briggs’ views that he would have not countenanced the continuation of CANH had he had the requisite capacity to make the decision. Mr. Briggs had not made an ADRT or an LPA – had a valid and applicable ADRT been made it would have been decisive and hence no best interests decision would have needed to be made (interestingly whilst there is much discussion within many MCS judgments about the use of ADRTs and LPAs, none of them had either of these in place).

In considering the best interests test, the judge drew upon the Supreme Court decision in *Aintree* which made it clear a holistic approach was to be taken in considering the patient’s welfare in the widest sense. He emphasized that the test was not a “what P would have done test,” but it was the best interests test requiring the decision-maker to perform a weighing or balancing exercise between a range of competing factors. It was still a “best interests” rather than a “substituted judgment” test, but he acknowledged that the preferences of the person involved were inevitably an important component in deciding where best interests ultimately lie (again noting the *Aintree* judgment which accepted the best interests test does include elements of a substituted judgment approach). He also stressed that a conclusion on what the person would have done was ultimately still not determinative of the best interests test.

The judge concluded that Mr. Briggs would have taken a realistic approach to his difficulties and that he would have been able to acknowledge the uncertainty with regard to recovery. Even with the best case scenario unfolding, he would still not have been able to lead an active or enjoyable

life. In the end, the decision came down to the presumption in favor of preserving life, versus the arguments as to what Mr. Briggs himself would have wanted had he the capacity to make such a decision. In weighing all the circumstances of the case, the judge concluded that the “weightiest and so determinative factor” in determining best interests was actually “what he would have wanted and done for himself.” He felt that Mr. Briggs “been sitting” in the judges’ chair hearing the arguments both for and against continuing his medical care, he would have opted to withdraw his CANH treatment. The court made declarations to this effect.

DISCUSSION

Because prolonged disorders of consciousness may result from various causes, there are no reliable statistics relating to incidence or prevalence. The current estimates range from 4000 to 16000 people in a VS, with treble the number in an MCS.^[11] Since the advent of the MCA, approximately two cases per year of MCS cases are being addressed by the courts for end-of-life decisions.^[23] The cases described demonstrate the legal approach and key themes in addressing these cases when they come to court [Box 6]. Due to the paucity of cases arriving at court, there is as yet little research into such cases. However, Huxtable and Birchley^[23] have provided an in-depth review of case law around the “(non-) treatment” of people in an MCS. They qualitatively analyzed the approaches courts take in deciding these cases and identified five key features. They observed that judges appeared to prefer “objective” and “scientific” expertise and evidence and particularly the views from doctors and that judges will not simply endorse a consensus reached by the parties involved in a case, reaching their own best interest decisions. They found that judges approached best interests assessments in different ways and that a balancing exercise was not consistently applied and even where it was, the weight accorded to particular factors varies – consequently, the “consistency and predictability of the law in this area is open to question.” Taylor^[24] similarly concurs that there is confusion as to the true meaning of “best interests” and inconsistencies in judicial interpretation persists. In similarly acknowledging that emerging MCS case law decisions may appear inconsistent and lack clarity of process, Samanta and Samanta^[25] analyze statute, common law and academic commentary to articulate a typology for elements that tend to engage in these decisions. In doing so, they developed a novel framework for holistic decision-making which has potentially far-reaching benefits such as improved consistency and transparency of decision-making producing a more uniform judicial approach.

The crux of these MCS cases is the best interests assessment. The Supreme Court has further affirmed that a court has no greater power to oblige others to do what was best than the person would have done himself if he had capacity, and it can only choose between available options.^[26] Recent case law has seen a clear sea change in emphasizing the importance of giving proper weight to a person’s wishes, feelings, beliefs,

and values as expounded under Section 4 (6);^[27-29] albeit, no court has yet imposed a hierarchy placing a person's wishes, feelings, values, and beliefs at the top of a best interests test.^[30]

The *Aintree* judgment noted that there are elements of a substituted judgment approach within the best interests test. The boundary between a best interests approach and a substituted judgment in both the Briggs and Bury cases appears to have been blurred. In both cases, such emphasis and weight were placed on the person's wishes, feelings, beliefs, and values; they appear in essence to have become substituted judgments albeit under the rubric of the best interests test. When assessing best interests, there is "no theoretical limit" to the weight or lack of weight that should be given to a person's wishes and feelings, beliefs, and values.^[27] Series^[30] suggests in these MCS cases that a hierarchy appears to be emerging within the best interests test placing the person's wishes, feelings, values, and beliefs above other competing considerations (the author noted that previous case law had rejected the opportunity to insert a rebuttable presumption that a person's wishes and feelings should hold sway).^[31] Ultimately, the weight a court will place on this aspect will in part relate to how much, and the quality of, information gleaned about the person (which can include pertinent emails from years previously^[32]) and can therefore appear to actually be determinative; in Bury, the judge opined where such quality information was obtained from family and friends, this should even be considered at the level of a capacitous person. This is a view also espoused by Coggon,^[33] who believes where a person's "reflectively endorsed" views on their interests are known, then legally this should hold equal weight regardless of whether they have capacity or not. The landmark ruling in Bury has been viewed as representing a shift in mental capacity law toward a substituted judgment test as opposed to a straightforward best interests test.^[34]

An anomaly has been described for there being "no apparent legal rationale" whereby VS (and similarly MCS) patients need to be referred to court for a final decision for withdrawal of CANH, but there is no such mandate for other life-sustaining treatments, e.g. antibiotics, CPR.^[35] A 10-year mortality review of patients in a VS/MCS who died in an English palliative care unit concluded that clinicians regularly undertake best interests decisions, often including life and death decisions, that may include the withdrawal or withholding of CANH, and that such decisions can be made under the current MCA framework without recourse for a court decision in all cases.^[36]

CONCLUSION

It is likely the future legal landscape in this area affecting people in a MCS will further evolve following the recent judgments in *M v A Hospital*^[37] and *NHS Trust v Y and Anor*,^[38] which suggest that VS/MCS cases need not be mandatorily referred to court for cessation of CANH (the latter case will likely be fast tracked to the Supreme Court for final resolution and interim guidance for health-care professionals has been issued^[39]) and the way best interests case law is rapidly evolving. Furthermore

the Law Commission^[40] has proposed amendments to Section 4 MCA in a draft Bill, currently being considered by the UK government, seeking to ensure that wishes and feelings must be given particular weight in best interests decision-making.

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There are no conflicts of interest.

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BOXES

Box 1: Key sections of the Mental Capacity Act 2005

Section 1: The principles

1. The following principles apply for the purposes of this Act
2. A person must be assumed to have capacity unless it is established that he lacks capacity
3. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success
4. A person is not to be treated as unable to make a decision merely because he makes an unwise decision
5. 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
6. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Section 2: People who lack capacity

To be judged to lack capacity, one must have “an impairment or disturbance of mind or brain functioning” (which can be permanent or temporary), which leaves a person unable to make a specific decision. A lack of capacity cannot be decided based solely upon a person's age, appearance, or behavior. Whether a person lacks capacity within the meaning of the Act is decided on the balance of probabilities.

Section 3: Inability to make decisions

This section sets out a four-stage test for making a capacitous decision. Assessment of capacity is decision specific. A person is unable to make a decision for himself if he is unable:

- a. To understand the information relevant to the decision
- b. To retain that information
- c. To use or weigh that information as part of the process of making the decision
- d. To communicate his decision (whether by talking, using sign language, or any other means).

If any limb of this test is not fulfilled, then the person is unable to make the specific decision in question.

The fact a person is only able to retain relevant information for a decision for only a short period does not prevent them from being regarded as able to make the decision.

The information relevant to a decision includes information about the reasonably foreseeable consequences of deciding one way or another or failing to make the decision.

Section 4: Best interests

This section sets out key factors that must *always* be considered when working out what is in someone's best interests. These factors are summarized in a checklist that is found in Chapter 5 (Paragraph 5.13) of the MCA Code of Practice:

- Working out what is in someone's best interests cannot be based simply on someone's age, appearance, condition, or behavior (Paragraphs 5.16–5.17)
- All relevant circumstances should be considered when working out someone's best interests (Paragraphs 5.18–5.20)
- Every effort should be made to encourage and enable the person who lacks capacity to take part in making the decision (Paragraphs 5.21–5.24)
- If there is a chance that the person will regain the capacity to make a particular decision, then it may be possible to put off the decision until later if it is not urgent (Paragraphs 5.25–5.28)
- Special considerations apply to decisions about life-sustaining treatment (including where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death) (Paragraphs 5.29–5.36)
- The person's past and present wishes and feelings, beliefs, and values should be taken into account (Paragraphs 5.37–5.48)
- The views of other people who are close to the person who lacks capacity should be considered, as well as the views of an attorney or deputy (Paragraphs 5.49–5.55).

The Code notes that the law cannot set out all factors that will need to be taken into account when working out someone's best interests because every case and every decision is different. Not all the factors in the checklist will be relevant to all types of decisions or actions.

The Code emphasizes that when working out best interests, it is vital not to take shortcuts – a proper and objective assessment must be carried out on every occasion.

The Code advises if the decision is urgent there may not be time to examine all possible factors, but the decision must still be made in the best interests of the incapacitous person.

Section 5: Acts in connection with care or treatment

This section protects or limits legal liability for people who are performing acts in connection with the care of those lacking capacity. Protection is assured provided the person acting for an incapacitous individual has taken reasonable steps to assess capacity, has a reasonable belief that person lacks capacity and that they are acting in his/her best interests.

*A full description of these and all sections of the MCA can be found at: <https://www.legislation.gov.uk/ukpga/2005/9/contents>

**The Mental Capacity Act Code of Practice can be viewed and downloaded at:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf

Box 2: Assessments to help differentiate between VS and MCS

The following assessments are expected to have been undertaken before application to court to help diagnostic rigor between VS and MCS.

1. Sensory Modality Assessment and Rehabilitation Technique – A validated assessment of diagnosing the level of awareness and consciousness in a patient with profound brain damage.
2. Wessex Head Injury Matrix (WHIM) – This is designed for the accurate assessment of patients in and emerging from coma and in the vegetative and minimally conscious states. The observational matrix can be used to assess the patient and set goals for rehabilitation from the outset of coma. In patients diagnosed as being in an MCS, a series of WHIM assessments need to have been carried out over time with a view to tracking the patient's progress and recovery (if any) of the MCS.

The *W v M* (2011)^[15] judgment sagely advised that in the future should an improved assessment scale be developed and becomes validated in medical literature for more accurately tracking recovery through an MCS, then this could be used in the place of the WHIM.

Box 3: Paragraph 5.31 of the Mental Capacity Act 2005 Code of Practice and sources of professional guidance

“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 the 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. Health-care and social-care staff should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment.”

Sources of professional guidance:

- General Medical Council (GMC) – Good Medical Practice^[41] and Treatment and care toward the end of life: good practice in decision-making^[42]
- British Medical Association (BMA) – Withholding and Withdrawing Life-prolonging Medical Treatment^[43]
- Royal College of Physicians – Prolonged disorders of consciousness: National clinical guidelines^[4]
- Chronic Disorders of Consciousness Research Centre^[44] – Serious medical decisions regarding people in vegetative or minimally conscious states. The role of family and friends.

A decision to withdraw clinically assisted nutrition and hydration, taken in accordance with the prevailing professional guidance at that time will be lawful and health-care professionals will benefit from the protection of Section 5 MCA.

Box 4: Key best interests assessment guidance emanating from the *Aintree v James*^[16] United Kingdom Supreme Court judgment

- The starting point is a strong presumption that it is in a person's best interests to stay alive. This is not an absolute, and there are cases where it will not be in the patient's interests to receive life-sustaining treatment
- The fundamental question is whether it is lawful to give the treatment, not whether it is lawful to withhold or withdraw it
- The purpose of the best interests test is to look at matters from the incapacitated person's point of view and ask what his attitude to the treatment is or would likely to be and to ascertain their individual values, likes, and dislikes
- Best interests should be considered in a holistic way – A person's welfare must be looked at in the widest sense, not just medical but social and psychological
- Decision makers must consult others who are looking after the person or are interested in their welfare, in particular for their view of what his attitude would be
- Best interests contains a strong element of “substituted judgment” taking into account both the past and present wishes of the patient, and also the factors which he would consider if able to do so – The preferences of the person concerned are an important component in deciding where his best interests lie

- The MCA 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.

Box 5: Best interests discourse from *M and Mrs N v Bury Clinical Commissioning Group*^[21]

“...where the wishes, views and feelings of P can be ascertained with reasonable confidence, they are always to be afforded great respect. That said, they will rarely, if ever, be determinative of P’s “best interests.” Respecting individual autonomy does not always require P’s wishes to be afforded predominant weight. Sometimes, it will be right to do so, sometimes it will not. The factors that fall to be considered in this intensely complex process are infinitely variable, e.g., the nature of the contemplated treatment, how intrusive such treatment might be and crucially what the outcome of that treatment may be for the individual patient. Into that complex matrix, the appropriate weight to be given to P’s wishes will vary. What must be stressed is the obligation imposed by statute to inquire into these matters and for the decision maker fully to consider them. Finally, I would observe that an assessment of P’s wishes, views and attitudes are not to be confined within the narrow parameters of what P may have said. Strong feelings are often expressed nonverbally, sometimes in contradistinction to what is actually said. Evaluating the wider canvass may involve deriving an understanding of P’s views from what he may have done in the past in circumstances which may cast light on the strength of his views on the contemplated treatment.”

Box 6: Key themes emanating from end-of-life minimally conscious state Court of Protection cases

- Minimally conscious state (MCS) is not just diagnosed in relation to an acute brain injury or similar but can be seen as part of other neurological and dementia disorders
- The MCA framework provides the basis for all decisions about medical treatment for those in a MCS
- All MCS cases considering withdrawal or withholding of clinically assisted nutrition and hydration (CANH) should currently be referred to the Court of Protection for final decisions
- The court can make binding declarations as to the lawfulness of treatment plans which may include withholding and withdrawal of active treatment and subsequent end-of-life care
- The court prefers that diagnostic issues should be resolved before application to the court, e.g. whether a VS or MCS
- While a person in an MCS may have a valid and applicable advance decisions to refuse treatment (ADRT), the case still needs to go to court for a decision to withhold or withdraw CANH
- Where a valid and applicable ADRT is in place, it will be decisive in the decision made by the court and no best interests approach would need to be applied
- The crux of these MCS cases is the application of the best interests ‘test’ where factors for and against a treatment plan are weighed using a balance sheet approach
- There has been increasing case law emphasizing the approach and weight given to ascertaining a person’s past and present wishes and feelings, beliefs, and values as part of the best interests assessment process.