

Prolonged Disorders of Consciousness



Medical advances mean that increasing numbers of people survive physical injury, stroke, periods of low oxygenation and severe brain infections. Some, however, are left with substantially reduced consciousness. This paper discusses the medical, legal and ethical challenges associated with the care of patients in vegetative and minimally conscious states.

Background

In 2020 the Royal College of Physicians (RCP) published updated National Clinical Guidelines for looking after patients with prolonged disorders of consciousness (PDoC).¹ The guidelines were endorsed by multiple stakeholders. This POSTnote focuses on the challenges associated with caring for adult patients with PDoC. This note provides an update on developments in this area, particularly in view of relevant legal judgments that have been given since the previous [POSTnote](#) on this topic in 2015.²

Defining disorders of consciousness

Consciousness is the state of being aware of and responsive to one's surroundings. Damage to the brain can result in disorders of consciousness on a spectrum that include coma, the vegetative state (VS) and the minimally conscious state (MCS). Patients can transition from one to the other and on to normal consciousness or remain in VS or MCS for a prolonged period, as detailed in Box 1. Coma is a state in which a person cannot be awakened and does not respond to any stimulation

Overview

- Prolonged disorders of consciousness (PDoC) include the vegetative state (no awareness) and the minimally conscious state (reduced awareness).
- The number of people in the UK with such conditions is unknown.
- Stakeholders have called for the collection of data on prognosis and outcomes for patients in PDoC to be mandated.
- Recent legal judgments emphasise the need to make 'best interests' decisions early about the harms and benefits of treatments, including clinically assisted nutrition and hydration (CANH). Research is needed into how to optimise this process, and how best to train those involved.
- There is no longer a legal requirement to go to court to withdraw CANH. However, there is no national oversight of these decisions and how they are recorded.

(including pain). Patients in a coma lack a normal sleep-wake cycle. Coma is not usually prolonged and is not covered here. Conditions that are not disorders of consciousness are described in Box 2.

- **Vegetative state (VS)** (sometimes termed Unresponsive Wakefulness Syndrome) is wakefulness without awareness. Patients have a sleep-wake cycle and may respond to stimulation with reflex (such as grasping) or spontaneous behaviours (such as grimacing). However, there is no environmental awareness or purposeful movement.
- **Minimally conscious state (MCS)** is wakefulness with minimal awareness. There is a broad spectrum of responsiveness within this umbrella term, ranging from patients who make a few non-reflex movements, to those who smile, cry or laugh in response to emotional stimuli, verbalise, or use objects (for example, a hairbrush) in a consistent, meaningful manner. Since 2002 there have been agreed clinical criteria for defining MCS,³ which can be further subcategorised as MCS with and without language.⁴

Box 1: Duration of prolonged disorders of consciousness

- **Continuing:** VS and MCS are said to be 'continuing' when they have lasted for more than four weeks. The term 'persistent' vegetative state has been used in the past but is no longer recommended.
- **Permanent:** VS and MCS are said to be permanent when there has been no change in responsiveness for at least 6 months. In these situations, recovery from this state is considered to be highly improbable (<1%).¹ VS and MCS can be diagnosed only by a suitably qualified consultant physician.

Diagnosis and prognosis**Clinical assessment**

Assessment of patients in PDoC is challenging and involves evaluation by specialist doctors and other health professionals.⁵ They observe patients for behaviours that suggest awareness of self or of their environment. Accurate prognosis (determining the likely outcome) is difficult for several reasons:

- patients often have accompanying mental or physical disabilities that may limit their ability to respond;⁶
- patients are often assessed when still medically unstable, which can cause their consciousness to fluctuate;⁷
- patients' responses are often delayed or inconsistent^{8,9}
- there is a degree of subjectivity in clinical observations.

Several assessment tools have been developed and validated to improve diagnostic accuracy.^{10–13} The Coma Recovery Scale-Revised (CRS-R) has the most comprehensive evidence base.^{11,14,15} All the tools require assessment by a multidisciplinary team, should ideally be carried out in specialist centres, and require repeated assessments over an adequate period of time, including at different times of day and involving stimulation of different senses. Assessments are best when they involve the family and care team who know the patient.⁷ Establishing a prognosis remains important for treatment and to support those close to the patient. Researchers are exploring how existing technologies might aid diagnosis and inform assessments of prognosis (see Box 3). The use of a brain imaging technology called functional MRI is used in many countries, and EEG is recommended in the European guidelines,¹⁵ but neither are currently recommended by the RCP; some clinicians and academics think they should be.¹⁶

Re-evaluation of patients

Experts agree that re-evaluation should occur at regular intervals (6 and 12 months, and yearly thereafter)¹⁷ to detect any changes in patients' awareness,¹⁸ and that evaluation should occur when the patient is physically well. The number of patients in nursing homes or cared for at home who have not

Box 2: Conditions that are not disorders of consciousness

- **Locked-in syndrome:** the patient is conscious, but paralysed.
- **Brainstem death:** there a loss of all consciousness and brainstem functions including spontaneous breathing. A ventilator can be used to maintain the body to allow organs to be donated, but the patient is considered medically and legally to be dead.⁴

Box 3: Investigations to aid diagnosis and prognosis

The uses of technologies to augment clinical evaluations of diagnosis and prognosis of PDoC are being researched.¹⁹ These technologies require specialist expertise. Most of the studies have been carried out in a single centre²⁰ and occur at a single time, despite patients' alertness varying considerably over time.

Functional MRI (fMRI)

Brain imaging using fMRI can assess responsiveness to stimuli and give some insight about the potential for a patient's recovery²¹ and level of awareness.^{22–25} There is still debate about whether it should be used routinely because:

- false negative results are common: 20% of fully conscious healthy volunteers are unable to generate fMRI activity;
- fewer than 15% of patients tested show previously unrecognised cognition, which may alter prognosis.^{1,21,26} It is not known whether the other 85% truly lack cognition, if brain arousal (at that particular time) is low, or whether they produce a false negative result.

Other technologies

Other approaches include specialised techniques to measure electrical activity in the brain (electroencephalography or EEG)^{27–31} or to examine its structural integrity (Diffusion Tensor Imaging). These tools can offer some insight into previously unrecognised cognition, causes of PDoC³² and prognosis,^{33,34} and are covered in [POSTnote 489](#).²

been formally re-evaluated since their initial diagnosis is unknown. Regular re-evaluation is critical to determine prognosis,^{17,35–37} direct appropriate rehabilitation, aid decision making about funding for continuing care and social care, and for decisions about withdrawal of treatment.

Understanding how many people have a PDoC

There are no reliable statistics on how many people are affected by PDoC; one reason for this is that it can result from numerous initial causes. Estimates of how many patients with a PDoC are admitted to specialist rehabilitation units in England each year range from 365³⁸ to 1,750.³⁹ By discharge, 43% have emerged into consciousness and demonstrate a wide range of disability. Although a few are thought to reach full independence, the majority remain severely dependent.¹⁸ Estimates (based on numbers of patients with PDoC in nursing homes in England and Wales) range from 4,000–16,000 patients in VS, with three times as many in a MCS. An unknown number of people with a PDoC are cared for in other settings, including at home.¹ Long-term follow up data is needed to improve treatments for PDoC, to better communicate prognosis and to direct funding more effectively. The RCP recommends that data should be collected for all patients who are in VS or MCS at the end of their initial assessment at 3 months post onset/injury with patient data being updated at least annually.¹ This information may be recorded in the UK Rehabilitation Outcomes Collaborative national clinical database for specialist rehabilitation. There have been calls from some stakeholders for use of the database to be mandated by the NHS.

Treatment

There are numerous medical and surgical interventions for an initial brain injury, and NICE recommends that patients in VS or MCS should be assessed in a specialist unit to identify and treat reversible causes.⁴⁰ Once a patient has been treated for the initial brain injury or event, and VS or MCS is established, they

will need personal care and are often fed with clinically assisted nutrition and hydration (CANH), for example via a tube into their stomach. They are looked after in a variety of settings, from specialist rehabilitation units to their own homes.

Other effective interventions are limited to specialist rehabilitation and care aimed at preventing complications. The drug amantadine has shown some promise for adults with traumatic brain injury (4–16 weeks post injury) to hasten functional recovery and reduce disability early in recovery.⁴¹ In the US, clinical guidance from the American Academy of Neurology recommends this drug.⁴² The RCP's guidance differs, suggesting that amantadine use be considered only under close monitoring, to observe the impact of the medication on that individual. Other experimental treatments are covered in [POSTnote 489](#) (2015).² No significant progress has been made since that publication.⁴³

Research into other treatments

No interventions have been proven to improve outcomes once patients are in an established PDoC. Research into novel treatments is difficult. No animal model exists where meaningful changes in consciousness can be assessed, and PDoC patients, by definition, cannot consent to a trial: interventions that are invasive or where the risks are unknown give rise to significant ethical concerns, although legal representatives can consent for some trials.

Rehabilitation

The RCP Guidelines recommend that patients with PDoC should be treated in specialist rehabilitation centres. The RCP notes that there are insufficient beds to meet demand.^{1,40} After this initial phase the guidelines promote a period of active surveillance in a specialist nursing home with specialist outreach monitoring and a 'revolving door' policy of readmission for rehabilitation if their condition changes. This is followed by annual review.

Supportive care for PDoC patients

Patients are prone to developing significant complications. These can be acute and reversible (such as some pneumonias), or chronic and less reversible (such as contractures, where muscles shorten because they have been tight for too long). To prevent or limit complications, 24-hour care involving a range of specialities is required, whether the patient is in an acute or long-term setting. Expertise can include: nutritional support, chest physiotherapy, management of airways (including tracheostomies), physiotherapy to maintain muscle tone and avoid contractures, occupational therapy for the provision of specialised equipment such as seating supports, speech and language therapy, and psychological support for patients and families.¹ Sitting in a wheelchair may help to increase patients' levels of arousal and potential to interact.⁴⁴ Supportive care includes specialist assessments of whether patients may be in pain or have depression, about which they are unable to communicate.^{45–50}

Providing and paying for care

The cost of treating patients with PDoC

The initial costs of treating and rehabilitating patients with PDoC are unknown. In 2015 it was estimated that it costed

£10,400 a month to look after a patient in permanent VS.⁵¹ Adjusted for inflation this would be at least £12,000 a month in 2022. Costs for MCS are likely to be similar, although individual patient expenditure will vary.

Commissioning and co-ordinating care

In England, the first 3–4 months of care is usually commissioned (paid for) by NHS England, with later care being provided by Local Commissioning groups.^{52,53} Some stakeholders state that there are problems with this model. Patients' needs for specialist services may last longer than this or come later, particularly in relation to the specialist end-of-life care they may require. In addition, conflicts of interest can exist in terms of paying for and supplying long-term care. For example, there are disincentives for organising specialist equipment such as chairs, as another commissioning body will bear the cost if it is done later. There are discrepancies in what will be provided if a patient receives their funding either through health or social care funding streams.

As a result, the RCP recommends that a 'network' model should be adopted, with centralisation of key skills in specialised centres, with key staff working both within institutions and in out-reach capacities.^{1,54} Adopting the national commissioning arrangements for specialised rehabilitation for patients with highly complex needs⁵² is suggested as one way of managing long-term care costs (in specialist nursing homes or elsewhere) for patients with PDoC.¹

Giving, withholding and withdrawing treatment

Decisions about when to give, withhold or end treatment are guided by the patient's past and (so far as ascertainable) present wishes, priorities and values (if known), professional ethics and codes of practice, and legislation and case law, described below. In England and Wales, a patient with the capacity⁵⁵ to make the relevant decision has the right to refuse but not to demand treatment;⁵⁶ to treat a patient against their will is considered assault⁵⁷ and to give a patient a treatment where the risks outweigh benefits is malpractice.⁵⁸ Common to other situations where patients lack capacity, stakeholders state that the challenge is how to apply these principles particularly when uncertainty often remains about diagnosis, prognosis and the benefits of various treatments.^{5,59}

Individual choice and best interests decisions

When patients have documented their preferences for future treatment in an advance statement, a binding Advance Decision to Refuse Treatment (see [POSTnote 481](#)),⁶⁰ or appointed a legal proxy, then medical decision-making for a person in a PDoC can be more straightforward. However, very few patients (under 5%)⁶¹ have done so. The Mental Capacity Act (MCA)^{55,62} instructs that in these circumstances doctors must follow a process⁶³ to act in the patient's best interests. This incorporates not only medical interests but 'the patient's welfare in the widest sense'. A judgment in the UK Supreme Court (*Aintree vs James*)⁶⁴ emphasised that the focus should be on whether it is in the patient's best interests and therefore lawful to *continue to give* rather than *withdraw* certain treatments. There is an obligation to review decisions on a regular basis.⁶⁵ If a facility has a 'pro-life' ethos and would not contemplate life-sustaining

treatment ever being withdrawn this does not absolve it of responsibility to determine whether those receiving care within it are being treated in their best interests.⁶⁶ The RCP provides guidance in relation to best interests meetings, which should involve both clinicians and those close to the patient. These meetings initiate conversations to establish what the patient's wishes might have been in these circumstances, and which treatments (from antibiotics to CANH) are in the patient's best interests.¹ There is no evidence on the optimal manner in which to conduct these meetings; more research could establish how best to sensitively establish the views of those close to the patient and the treating clinicians.⁶⁷ There is agreement that best interest meetings should be held routinely, when treatment decisions are needed, with rapid referral to the Court of Protection when there is any disagreement between those present about what is in the patient's best interests or where the decision is finely balanced.⁶⁸

Public attitudes

Information about public attitudes is limited but some themes have emerged from charities' work.^{69,70} Enquiries to Compassion in Dying⁷¹ (a charity that provides information and support around end-of-life rights and choices) doubled after media stories about patients in MCS were published.⁷² Those contacting the charity often express a desire not to become 'a vegetable' as the motivation for completing an advance decision document. However some people don't feel confident that they would be able to accurately predict what they would want in a future state, and prefer to leave the decision to clinicians.⁷³ Interviews with families on the website Healthtalk highlight several other issues.⁷⁴ Family members have diverse views, with some believing in much more positive outcomes than are likely⁷⁴ and some feeling that their relative has recovered sufficiently to gain pleasure from some activities and that ongoing treatment is justified. Others believe that their relative would not have wanted to survive in their condition.⁷⁵ Rarely, some have attempted to end the patient's life because they believe that that is what the individual would have wanted.⁷⁶

Considerations around withdrawing clinically assisted nutrition and hydration (CANH)

Treatments to support or prolong life, such as ventilation, dialysis or cardiopulmonary resuscitation may only be given when there is evidence of benefit of these treatments to the patient. They are withdrawn when clinicians and family are in agreement that the patient would not benefit from them.^{77,78} CANH has historically been treated differently from withdrawal of other treatments, perhaps because the mode of dying is very different, particularly in a brain-damaged patient whose body is in good health and well nourished. The death can be protracted (up to three weeks); it is sometimes associated with physiological responses that are unpleasant for carers or loved ones to witness (such as grimacing, sweating and involuntary movements); and it renders the organs unsuitable for donation, which can compound a family's distress.⁷⁹

Changes resulting from legal rulings

A series of legal rulings about whether CANH could be withdrawn from people affected by PDoC have changed how decisions about their treatment are made, see Box 4. Following the case of Tony Bland in 1993⁸⁰ an application to court was

understood to be required before CANH could be withdrawn from a patient in a permanent VS. From 2007 this was the Court of Protection. In 2016 in the case of Briggs, the court approved removing CANH from a patient in an MCS.⁸¹

In its 2018 ruling, in a case called *Re Y*, The UK Supreme Court ruled that there was no legal obligation to approach the court for endorsement of the decision where there was agreement of medical opinion, agreement about the proposed course of action among those with an interest in the patient's welfare, and where the decisions were not 'finely balanced'.⁸² In all other situations, applications to the court were encouraged.⁸³ The number or distribution of patients in whom the decision to withdraw CANH has been made without recourse to the courts is not known, and there is no clear national governance or oversight for this.⁸⁴ Stakeholders comment that if the proposed registry of PDoC patients included outcomes and mode of death then this data could be synthesised and audited.

Box 4: Legal rulings about PDoC patients

Airedale NHS Trust v. Bland, 1993⁸⁰

Tony Bland, injured at the Hillsborough disaster, was in persistent VS; his family did not think he would want to continue in this state, and appealed to the House of Lords, who ruled that his CANH was not providing benefit and should be stopped, with the inevitable consequence of death. Following this decision, at least 100 cases were taken to court to determine whether CANH was in the patient's interests or should be withdrawn from patients in a VS.

Briggs v. Briggs, 2016⁸¹

Mr Briggs was in a MCS after a brain injury. Mrs Briggs sought a ruling as to whether it was in her husband's best interests to continue to be given CANH or to be moved to a hospice where he would receive palliative care but no further CANH, and would, as a result, die. The judge concluded, drawing heavily on his consideration of what decision Mr Briggs would have made, that the latter path was in his best interests.

An NHS Trust & Others v. Y, 2018⁸²

The use of the courts to routinely decide whether CANH can be withdrawn for patients with PDoC cases was examined by the UK Supreme Court in 2018. The Supreme Court confirmed that that neither common law or the European Convention on Human Rights separately or in combination, gave rise to a mandatory requirement for a court to be involved in deciding whether CANH can be withdrawn. It further confirmed that no application was required if the provisions of the MCA 2005 are followed and the relevant guidance observed, and if there is agreement upon what is in the patient's interests.

Beyond the withdrawal of treatment

Some family members have argued that if a court is prepared to authorise withdrawal of CANH (following which death is inevitable), it should also be able to authorise terminal sedation, although this would not currently be legal if the intention is to hasten death. Terminal sedation would allow a predictable time of death (with family present if desired), fewer manifestations of physiological distress, and potential organ donation.⁸⁵ This is particularly relevant if it is considered that an individual's 'best interests' can extend beyond their own bodily integrity, for example to the wellbeing of those close to them⁸⁶ and to their own legacy after death.⁸⁷

References

1. [Prolonged disorders of consciousness following sudden onset brain injury: national clinical guidelines | RCP London.](#)
2. Fritz, Z. *et al.* (2015). [Vegetative and Minimally Conscious States.](#) Parliamentary Office of Science & Technology, UK Parliament.
3. Giacino, J. T. *et al.* (2002). [The minimally conscious state: definition and diagnostic criteria.](#) *Neurology*, Vol 58, 349–353.
4. (2010). [A code of practice for the diagnosis and confirmation of death.](#) *Academy of Medical Royal Colleges.*
5. Harvey, D. *et al.* (2018). [Management of perceived devastating brain injury after hospital admission: a consensus statement from stakeholder professional organizations.](#) *British Journal of Anaesthesia*, Vol 120, 138–145. Elsevier.
6. Majerus, S. *et al.* (2009). [The problem of aphasia in the assessment of consciousness in brain-damaged patients.](#) in *Progress in Brain Research.* (eds. Laureys, S. *et al.*) Vol 177, 49–61. Elsevier.
7. (2020). [Prolonged disorders of consciousness following sudden onset brain injury: national clinical guidelines.](#) *RCP London.*
8. Childs, N. L. *et al.* (1993). [Accuracy of diagnosis of persistent vegetative state.](#) *Neurology*, Vol 43, 1465–1467.
9. Shiel, A. *et al.* (2000). [The Wessex Head Injury Matrix \(WHIM\) main scale: a preliminary report on a scale to assess and monitor patient recovery after severe head injury.](#) *Clin Rehabil*, Vol 14, 408–416.
10. American Congress of Rehabilitation Medicine, Brain Injury-Interdisciplinary Special Interest Group, Disorders of Consciousness Task Force *et al.* (2010). [Assessment scales for disorders of consciousness: evidence-based recommendations for clinical practice and research.](#) *Arch Phys Med Rehabil*, Vol 91, 1795–1813.
11. Giacino, J. T. *et al.* (2004). [The JFK Coma Recovery Scale-Revised: measurement characteristics and diagnostic utility.](#) *Arch Phys Med Rehabil*, Vol 85, 2020–2029.
12. Wilson, F. C. *et al.* (2009). [Analysis of Wessex Head Injury Matrix \(WHIM\) scores in consecutive vegetative and minimally conscious state patients.](#) *Neuropsychol Rehabil*, Vol 19, 754–760.
13. Gill-Thwaites, H. *et al.* (2004). [The Sensory Modality Assessment and Rehabilitation Technique \(SMART\): a valid and reliable assessment for vegetative state and minimally conscious state patients.](#) *Brain Inj*, Vol 18, 1255–1269.
14. Lucca, L. F. *et al.* (2019). [Outcome prediction in disorders of consciousness: the role of coma recovery scale revised.](#) *BMC Neurology*, Vol 19, 68.
15. Kondziella, D. *et al.* (2020). [European Academy of Neurology guideline on the diagnosis of coma and other disorders of consciousness.](#) *Eur J Neurol*, Vol 27, 741–756.
16. Scolding, N. *et al.* (2021). [Prolonged disorders of consciousness: a critical evaluation of the new UK guidelines.](#) *Brain*, Vol 144, 1655–1660.
17. Hirschberg, R. *et al.* (2011). [The vegetative and minimally conscious states: diagnosis, prognosis and treatment.](#) *Neurol Clin*, Vol 29, 773–786.
18. McCrea, M. A. *et al.* (2021). [Functional Outcomes Over the First Year After Moderate to Severe Traumatic Brain Injury in the Prospective, Longitudinal TRACK-TBI Study.](#) *JAMA Neurology*, Vol 78, 982–992.
19. Sanz, L. R. D. *et al.* (2021). [Update on neuroimaging in disorders of consciousness.](#) *Current Opinion in Neurology*, Vol 34, 488–496.
20. Kondziella, D. *et al.* (2016). [Preserved consciousness in vegetative and minimal conscious states: systematic review and meta-analysis.](#) *J Neurol Neurosurg Psychiatry*, Vol 87, 485–492.
21. Coleman, M. R. *et al.* (2009). [Towards the routine use of brain imaging to aid the clinical diagnosis of disorders of consciousness.](#) *Brain*, Vol 132, 2541–2552.
22. Monti, M. M. *et al.* (2010). [Willful Modulation of Brain Activity in Disorders of Consciousness.](#) *New England Journal of Medicine*, Vol 362, 579–589.
23. Fernández-Espejo, D. *et al.* (2011). [Diffusion weighted imaging distinguishes the vegetative state from the minimally conscious state.](#) *Neuroimage*, Vol 54, 103–112.
24. Owen, A. M. *et al.* (2008). [Detecting awareness in the vegetative state.](#) *Ann. N. Y. Acad. Sci.*, Vol 1129, 130–138.
25. Naci, L. *et al.* (2013). [Making every word count for nonresponsive patients.](#) *JAMA Neurol*, Vol 70, 1235–1241.
26. Schnakers, C. *et al.* (2020). [Covert Cognition in Disorders of Consciousness: A Meta-Analysis.](#) *Brain Sci*, Vol 10, 930.
27. Cruse, D. *et al.* (2011). [Bedside detection of awareness in the vegetative state: a cohort study.](#) *Lancet*, Vol 378, 2088–2094.
28. Cruse, D. *et al.* (2012). [Detecting Awareness in the Vegetative State: Electroencephalographic Evidence for Attempted Movements to Command.](#) *PLOS ONE*, Vol 7, e49933.
29. Sitt, J. D. *et al.* (2014). [Large scale screening of neural signatures of consciousness in patients in a vegetative or minimally conscious state.](#) *Brain*, Vol 137, 2258–2270.
30. Landsness, E. *et al.* (2011). [Electrophysiological correlates of behavioural changes in vigilance in vegetative state and minimally conscious state.](#) *Brain*, Vol 134, 2222–2232.
31. Claassen, J. *et al.* (2019). [Detection of Brain Activation in Unresponsive Patients with Acute Brain Injury.](#) *N Engl J Med*, Vol 380, 2497–2505.
32. Newcombe, V. F. J. *et al.* (2010). [Aetiological differences in neuroanatomy of the vegetative state: insights from diffusion tensor imaging and functional implications.](#) *J. Neurol. Neurosurg. Psychiatry*, Vol 81, 552–561.
33. Luyt, C.-E. *et al.* (2012). [Diffusion tensor imaging to predict long-term outcome after cardiac arrest: a bicentric pilot study.](#) *Anesthesiology*, Vol 117, 1311–1321.
34. Galanaud, D. *et al.* (2012). [Assessment of white matter injury and outcome in severe brain trauma: a prospective multicenter cohort.](#) *Anesthesiology*, Vol 117, 1300–1310.
35. Giacino, J. T. (2004). [The vegetative and minimally conscious states: consensus-based criteria for establishing diagnosis and prognosis.](#) *NeuroRehabilitation*, Vol 19, 293–298.
36. Whyte, J. *et al.* (2013). [Disorders of consciousness: outcomes, comorbidities, and care needs.](#) *Arch Phys Med Rehabil*, Vol 94, 1851–1854.
37. Katz, D. I. *et al.* (2009). [Natural history of recovery from brain injury after prolonged disorders of consciousness: outcome of patients admitted to inpatient rehabilitation with 1–4 year follow-up.](#) in *Progress in Brain Research.* (eds. Laureys, S. *et al.*) Vol 177, 73–88. Elsevier.
38. Turner-Stokes, L. *et al.* (2022). [Prolonged disorders of consciousness: identification using the UK FIM + FAM and cohort analysis of outcomes from a UK national clinical database.](#) *Disability and Rehabilitation*, Vol 0, 1–10. Taylor & Francis.

39. Wade, D. T. (2018). [How many patients in a prolonged disorder of consciousness might need a best interests meeting about starting or continuing gastrostomy feeding?](#) *Clin Rehabil*, Vol 32, 1551–1564. SAGE Publications Ltd STM.
40. (2007). [Head injury: Triage, assessment, investigation and early management of head injury in infants, children and adults: Guidance.](#) NICE.
41. Whyte, J. *et al.* (2005). [Predictors of outcome in prolonged posttraumatic disorders of consciousness and assessment of medication effects: A multicenter study.](#) *Arch Phys Med Rehabil*, Vol 86, 453–462.
42. American Academy of Neurology (2018). [Practice Guideline Update Recommendations Summary: Disorders of Consciousness.](#)
43. Edlow, B. L. *et al.* (2021). [Therapies to Restore Consciousness in Patients with Severe Brain Injuries: A Gap Analysis and Future Directions.](#) *Neurocrit Care*, Vol 35, 68–85.
44. (2020). [Prolonged Disorders of Consciousness following Sudden Onset Brain Injury: National Clinical Guidelines. Annex 2c Optimising conditions for response.](#) Royal College of Physicians.
45. Hammond, M. F. *et al.* (2000). [Development and validation of a brief observer-rated screening scale for depression in elderly medical patients.](#) *Age Ageing*, Vol 29, 511–515.
46. Abbey, J. *et al.* (2004). [The Abbey pain scale: a 1-minute numerical indicator for people with end-stage dementia.](#) *Int J Palliat Nurs*, Vol 10, 6–13.
47. Warden, V. *et al.* (2003). [Development and psychometric evaluation of the Pain Assessment in Advanced Dementia \(PAINAD\) scale.](#) *J Am Med Dir Assoc*, Vol 4, 9–15.
48. Turner-Stokes, L. *et al.* (2005). [The Depression Intensity Scale Circles \(DISCs\): a first evaluation of a simple assessment tool for depression in the context of brain injury.](#) *J Neurol Neurosurg Psychiatry*, Vol 76, 1273–1278.
49. Schnakers, C. *et al.* (2010). [The Nociception Coma Scale: a new tool to assess nociception in disorders of consciousness.](#) *Pain*, Vol 148, 215–219.
50. (2005). [Antidepressant medication use in adults undergoing recovery and rehabilitation following acquired brain injury.](#) Royal College of Physicians.
51. A. Formby *et al.* (2015). [Cost Analysis of the Legal Declaratory Relief Requirement for Withdrawing Clinically Assisted Nutrition and Hydration \(CANH\) from Patients in the Permanent Vegetative State \(PVS\) in England and Wales.](#) Centre for Health Economics, University of York.
52. [NHS commissioning - Specialised services.](#)
53. Parkin, E. *et al.* (2020). [The structure of the NHS in England.](#) House of Commons Library, UK Parliament.
54. Nyein, K. *et al.* (2019). [British society of rehabilitation medicine 2018 annual scientific meeting Brighton, 8–10 October 2018, Outreach assessment services: potential cost savings from inappropriate admission to specialist rehabilitation.](#) *Clin Rehabil*, Vol 33, 1978–1985. SAGE Publications Ltd STM.
55. (2005). [Mental Capacity Act 2005.](#)
56. (2005). [Burke, R \(on the application of\) v General Medical Council & Ors \[2005\] EWCA Civ 1003.](#)
57. (1990). [F v West Berkshire HA \[1991\] UKHL 1.](#)
58. (1957). [Bolam v Friern Hospital Management Committee \[1957\] All ER 713.](#)
59. van Veen, E. *et al.* (2021). [Occurrence and timing of withdrawal of life-sustaining measures in traumatic brain injury patients: a CENTER-TBI study.](#) *Intensive Care Med*, Vol 47, 1115–1129.
60. Abbi Hobbs (2014). [Palliative and End of Life Care.](#) Parliamentary Office of Science & Technology, UK Parliament.
61. Knight, T. *et al.* (2020). [Advance care planning in patients referred to hospital for acute medical care: Results of a national day of care survey.](#) *EClinicalMedicine*, Vol 19, 100235.
62. Gareth Owen *et al.* (2011). [Mental Capacity and Healthcare.](#) Parliamentary Office of Science & Technology.
63. (2015). [Mental Capacity Assessment Tool Guidance.](#) NHS.
64. (2013). [Aintree University Hospitals NHS Foundation Trust v James \[2013\] UKSC 67.](#)
65. (2021). [North West London Clinical Commissioning Group v GU \[2021\] EWCOP 59.](#)
66. (2019). [A Clinical Commissioning Group v P \(Withdrawal of CANH\) \[2019\] EWCOP 18.](#)
67. (2012). [Best Interests Decisions Study: Lay Summary.](#) Mental Health Foundation; Norah Fry Research Centre, University of Bristol; University of Bradford.
68. Wade, D. T. *et al.* (2019). [Making healthcare decisions in a person's best interests when they lack capacity: clinical guidance based on a review of evidence.](#) *Clin Rehabil*, Vol 33, 1571–1585. SAGE Publications Ltd STM.
69. Demertzi, A. *et al.* (2011). [Attitudes towards end-of-life issues in disorders of consciousness: a European survey.](#) *J. Neurol.*, Vol 258, 1058–1065.
70. Constable, C. (2012). [Withdrawal of artificial nutrition and hydration for patients in a permanent vegetative state: changing tack.](#) *Bioethics*, Vol 26, 157–163.
71. [Compassion in Dying.](#)
72. [Compassion in Dying \(2015\).](#) Personal Communication.
73. Ditto, P. *et al.* (2005). [Imagining the End of Life: On the Psychology of Advance Medical Decision Making.](#) *Motivation & Emotion*, Vol 29, 475–496.
74. Healthtalk.org [Family Experiences of Vegetative and Minimally Conscious States.](#) *Family Experiences of Vegetative and Minimally Conscious States - Overview.*
75. Kitzinger, J. *et al.* (2013). [The 'window of opportunity' for death after severe brain injury: family experiences.](#) *Social Health Illn*, Vol 35, 1095–1112.
76. (2010). [Inglis, R v \[2010\] EWCA Crim 2637.](#)
77. Lewis, P. (2007). [Withdrawal of treatment from a patient in a permanent vegetative state: judicial involvement and innovative 'treatment': an NHS Trust v. J.](#) *Med Law Rev*, Vol 15, 392–399.
78. (2010). [Treatment and care towards the end of life: good practice in decision making.](#)
79. Kitzinger, J. *et al.* (2018). [Deaths after feeding-tube withdrawal from patients in vegetative and minimally conscious states: A qualitative study of family experience.](#) *Palliat Med*, Vol 32, 1180–1188.
80. Great Britain. House of Lords (1993). [Airedale NHS Trust v. Bland.](#) *All Engl Law Rep*, Vol [1993]1, 821–896.
81. (2016). [In the Matter of S21A of the Mental Capacity Act 2005 and in the Matter of Paul Briggs.](#) 38.
82. (2018). [An NHS Trust and others v Y & another \[2018\] UKSC 46.](#)
83. [Serious Medical Treatment, Guidance \[2020\] EWCOP 2 \(17 January 2020\) \(bailii.org\).](#)
84. Gray, A. *et al.* (2021). [Absence of monitoring in withdrawal of clinically-assisted nutrition and hydration \(CANH\) and other treatments: a cause for concern?](#) *Clin Med (Lond)*, Vol 21, 235–237.
85. Kitzinger, C. *et al.* (2015). [Withdrawing artificial nutrition and hydration from minimally conscious and vegetative patients: family perspectives.](#) *J Med Ethics*, Vol 41, 157–160.

86. Fritz, Z. (2017). [Can 'Best Interests' derail the trolley? Examining withdrawal of clinically assisted nutrition and hydration in patients in the permanent vegetative state.](#) *Journal of Medical Ethics*, Vol 43, 450–454. Institute of Medical Ethics.
87. *Re M [2009] EWHC 2525 (Fam) (particularly paragraph para 38).*