



Royal College  
of Physicians

**Prolonged disorders  
of consciousness  
following sudden  
onset brain injury:**  
National clinical guidelines

**Setting higher standards**

Report of a working party 2020





**Royal College  
of Physicians**

# **Prolonged disorders of consciousness following sudden onset brain injury: National clinical guidelines**

**Report of a working party 2020**

**Endorsed by:**

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- > Association for Palliative Medicine
- > British Geriatric Society
- > British Psychological Society
- > British Society of Rehabilitation Medicine
- > Chartered Society of Physiotherapists
- > Faculty of Intensive Care Medicine
- > Royal College of Occupational Therapists
- > Royal College of Nursing
  - RCN Pain and Palliative Care Forum
  - RCN Neuroscience Nursing Forum
- > Royal College of Physicians
- > Royal College of Speech and Language Therapists
- > Society of British Neurological Surgeons
- > Society for Research in Rehabilitation

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- > The Association of British Neurologists
- > The British Medical Association

Setting higher standards

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### Citation for this document:

Royal College of Physicians. *Prolonged disorders of consciousness following sudden onset brain injury: National clinical guidelines*. London: RCP, 2020.

### Review date: 2025

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ISBN 978-1-86016-793-5  
eISBN 978-1-86016-794-2

Royal College of Physicians  
11 St Andrews Place  
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London NW1 4LE  
[www.rcplondon.ac.uk](http://www.rcplondon.ac.uk)

Registered Charity No 210508

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### Working party remit

The objectives of this working party are to update and clarify the Royal College of Physicians' (RCP's) *Prolonged disorders of consciousness, National clinical guidelines (2013)*,<sup>1</sup> particularly in relation to recent developments in assessment and management; and with respect to recent changes in the law governing procedures for the withdrawal of clinically assisted nutrition and hydration (CANH).

### The guideline covers

- > Definitions and terminology of prolonged disorders of consciousness (PDOC)
- > Techniques for assessment, diagnosis and review
- > Care pathways from acute to long-term management
- > The ethical and medico-legal framework for decision-making
- > Practical decision-making regarding starting or continuing life-sustaining treatments, including CANH, and management of end-of-life care for PDOC patients
- > Service organisation and commissioning.

The guideline also makes recommendations for development of a register and an agreed minimum dataset to gather systematic longitudinal data in order to identify factors that predict outcome and emergence from a minimally conscious state.

### Guideline Development Group

The multidisciplinary Guideline Development Group (GDG) included representation of patients/users and a wide range of stakeholders and professionals involved in the management of patients with PDOC.

GDG membership was selected to provide a broad range of views and opinions, especially with respect to the more challenging issues, such as ethics and end-of-life decisions.

The GDG met on four occasions. The RCP provided a meeting room and refreshments, but GDG members were generally expected to fund their own time and travel expenses, or to seek funding from their affiliated organisations.

### Relevance to UK countries

While these guidelines can be adopted for use by all UK countries, commissioning arrangements are pertinent to NHS England and Clinical Commissioning Groups in England.

## GDG membership

Core Executive and Editorial Group (CEEG)	Representation
<p><b>Professor Lynne Turner-Stokes MBE</b> (chair)            Consultant in rehabilitation medicine, Northwick Park Hospital;            Northwick Park professor of rehabilitation medicine, King's            College London</p>	<p>Royal College of Physicians            and British Society of            Rehabilitation Medicine</p>
<p><b>Professor Derick Wade</b> (co-chair)            Professor of neurological rehabilitation, Oxford Brookes            University</p>	<p>Association of British            Neurologists</p>
<p><b>Professor Diane Playford</b> (co-chair)            Professor in neurological rehabilitation, Warwick University</p>	<p>Association of British            Neurologists</p>
<p><b>Professor Jenny Kitzing</b> (coordinator for service user input)            Professor of communications research, Cardiff University;            (Also, <b>Professor Celia Kitzing</b>, fellow of the British            Psychological Society, acting as alternate)</p>	<p>Coma and Disorders of            Consciousness Research            Centre, Cardiff University</p>
<p><b>Dr Judith Allanson</b>            Consultant in rehabilitation medicine, Cambridge</p>	<p>British Society of            Rehabilitation Medicine</p>
<p><b>Amy Pundole</b>            Speech and language therapist</p>	<p>Royal College of Speech and            Language Therapists</p>
<p><b>Dr Andrew Hanrahan</b>            Consultant in rehabilitation medicine, Royal Hospital for            Neurodisability, Putney</p>	<p>British Society of            Rehabilitation Medicine</p>
<p><b>Jakki Cowley</b>            Mental capacity advocate, Empowerment Matters</p>	<p>Empowerment Matters</p>
<p><b>Dr Lucy Pollock</b>            Consultant geriatrician</p>	
<p><b>Dr Chris Danbury</b>            Consultant in anaesthetics and intensive care, Royal Berkshire            Hospital</p>	<p>Faculty of Intensive Care            Medicine</p>
<p><b>Dr Karen Elliott</b>            Occupational therapist, Gill-Thwaites &amp; Elliott Consultants</p>	<p>Royal College of Occupational            Therapists</p>
<p><b>Professor Rob George</b>            Professor of palliative care, King's College London;            consultant in palliative care, Guy's and St Thomas' NHS            Foundation Trust, London</p>	<p>Association for Palliative            Medicine;            Royal College of Physicians            ethics lead</p>

## Working party remit

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<b>Core Executive and Editorial Group (CEEG)</b>	<b>Representation</b>
<b>Helen Gill Thwaites MBE</b> Occupational therapist, Royal Hospital for Neurodisability, Putney	
<b>Dr Shuli Levy</b> Consultant physician and geriatrician, Imperial College Healthcare NHS Trust	British Geriatric Society
<b>Dr Stephen Ashford</b> Consultant physiotherapist, Northwick Park Hospital; senior clinical lecturer, University College London Hospitals	The Chartered Society of Physiotherapy The Society for Research in Rehabilitation
<b>Professor Tom McMillan</b> Professor of clinical neuropsychology, Institute of Health and Wellbeing, University of Glasgow	The British Psychological Society
<b>Professor John Pickard</b> Emeritus professor of neurosurgery and honorary director of the NIHR Brain Injury MedTech Cooperative	Society of British Neurological Surgeons
<b>Dr Neil Roberts</b> GP, Sawbridgeworth, Hertfordshire	
<b>Keith Sephton</b> Database manager, UK Rehabilitation Outcomes Collaborative	UKROC database manager
<b>Wendy Stuttle</b> Physiotherapist, specialist nursing home manager, Ramsay Healthcare UK	
<b>Dr Krystyna Walton</b> Consultant in neurorehabilitation, Salford Royal NHS Foundation Trust	British Society of Rehabilitation Medicine
<b>Carolyn Young</b> Specialised commissioner; NHSE/I responsible commissioner for specialist rehabilitation (including PDOC services)	NHS England
<b>Sally Plumb</b> Registered nurse and case manager – complex rehabilitation; specialised commissioning – NHS England South (South West Hub)	NHS England Royal College of Nursing
<b>Jean Gaffin</b> PCN member on the RCP JSC for Rehabilitation Medicine	Royal College of Physicians
<b>Legal advisers</b>	
<b>Alex Ruck Keene</b> Barrister, 39 Essex Chambers; visiting lecturer, King's College London	

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### **Core Executive and Editorial Group (CEEG)**

### **Representation**

#### **Yogi Amin**

Partner and national head, Public Law and Human Rights, Irwin Mitchell LLP

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### ***Ex officio* members from the RCP**

#### **Professor Andrew Goddard** (*ex officio*)

President, Royal College of Physicians

Royal College of Physicians

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#### **Professor Donal O'Donoghue** (*ex officio*)

Registrar, Royal College of Physicians

Royal College of Physicians

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### **Support to the GDG provided by the following Royal College of Physicians staff members:**

**Linda Cuthbertson** Head of strategic communications

**Simon Land / Howard Ellison / Rhys Owens**

Consultation and committee services

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JSC = Joint Specialty Committee; PCN = Patient and Carer Network

### Conflicts of interest

Any conflicts of interest were fully declared and are available from the authors. A 'Declaration of interests' form was completed by all GDG members who were also reminded of the need to disclose any potential new conflicts of interest as these arose.

In summary, none of the GDG members has any personal financial interest in the recommendations put forward in this guidance.

- > None of the GDG members were affiliated with any pro-life or pro-euthanasia group.
- > Two members of the group, Helen Gill-Thwaites and Karen Elliott, were the originators of the Sensory Modality Assessment and Rehabilitation Technique (SMART).
- > Six members (Andrew Hanrahan, Karen Elliott, Helen Gill, Shuli Levy, Lynne Turner-Stokes and Derick Wade) regularly provide independent opinions and have acted as expert witnesses in applications to the court relating to withdrawal of clinically assisted nutrition and hydration; and Jenny and Celia Kitzinger provide support to patients and families for *best interests* discussions and court procedures, including acting as litigation friend in court.
- > Two members act in legal cases involving decisions about life-sustaining treatments:
  - Yogi Amin regularly acts as a lawyer in applications to the court for withdrawal of clinically assisted nutrition and hydration.
  - Alex Ruck Keene was involved in the application that led to the decision of the Supreme Court that such cases do not automatically need to come to court. He also sits on the Court of Protection Rules Committee.
- > Many of the GDG members are working within NHS or independent provider settings to offer services for patients in PDOC.
- > Some GDG members are actively involved in research in this area.
- > Some GDG members have personal experience of living with / caring for a person in a vegetative state (VS) or minimally conscious state (MCS).
- > All GDG members are primarily concerned with improving the quality of care offered to patients with PDOC and their families.

## Stakeholder organisations

**These guidelines are endorsed by the following organisations:**

- > Association for Palliative Medicine
- > British Geriatric Society
- > British Psychological Society
- > British Society of Rehabilitation Medicine
- > Chartered Society of Physiotherapists
- > Faculty of Intensive Care Medicine
- > Royal College of Occupational Therapists
- > Royal College of Nursing\*
  - RCN Pain and Palliative Care Forum
  - RCN Neuroscience Nursing Forum
- > Royal College of Physicians
- > Royal College of Speech and Language Therapists
- > Society of British Neurological Surgeons
- > Society for Research in Rehabilitation

**They are also supported by:**

- > The Association of British Neurologists
- > The British Medical Association



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\* The guidelines have been reviewed by the both the Royal College of Nursing (RCN) Pain and Palliative Care Forum and the RCN Neuroscience Nursing Forum.

## Methodology

A summary of the methodology of guideline development according to the Appraisal of Guidelines for Research and Evaluation (AGREE) guidelines<sup>2</sup> is given in Table 0.1.

The evidence typology developed for the National Service Framework for Long Term Conditions<sup>3</sup> was used to grade the evidence and formulate the recommendations.

Further details of guideline methodology are given in Appendix 1.

## Administration

Guideline development was led through the Royal College of Physicians (RCP) and the British Society of Rehabilitation Medicine (BSRM).

- > The GDG was administrated as a working party through the Membership Support and Global Engagement department of the RCP.

## Drafting of the report

Professor Lynne Turner-Stokes, as chair of the GDG, was responsible for the overall drafting of the final guideline document.

Other members of the GDG contributed to progress the draft guidelines in between meetings

## Acknowledgements

The GDG would like to thank all of the patients, their families and the multidisciplinary teams whose collective experience has gone into the formulation of these clinical guidelines.

On behalf of the RCP and other nominating organisations, we would like to thank the GDG and subgroup members who gave freely of their time to contribute to the substantial work involved in the development of these guidelines.

## Guideline development process

The guidelines have been developed in accordance with the principles laid down by the AGREE collaboration<sup>2</sup> as summarised in Table 0.1.

**Table 0.1 Summary of methodology for the guidelines development according to the AGREE guidelines**

<b>Scope and purpose</b>	
<b>Overall objective of the guidelines</b>	To update and clarify the RCP's <i>Prolonged disorders of consciousness, National clinical guidelines</i> (2013), particularly in relation to recent developments in assessment and management; and with respect to recent changes in the law governing procedures for the withdrawal of clinically assisted nutrition and hydration (CANH) and other life-sustaining treatments.
<b>The patient group covered</b>	Adult patients (16 years and over) with PDOC, including VS and MCS.
<b>Target audience</b>	Clinicians, commissioners and providers of services for people with PDOC following profound brain injury.
<b>Clinical areas covered</b>	<ul style="list-style-type: none"> <li>&gt; Definitions and terminology of PDOC</li> <li>&gt; Techniques for assessment, diagnosis and review</li> <li>&gt; Care pathways from acute to long-term management</li> <li>&gt; The ethical and medico-legal framework for decision-making</li> <li>&gt; Practical decision-making regarding starting, restarting, stopping or continuing life-sustaining treatments, including CANH, and management of end-of-life care for patients with PDOC</li> <li>&gt; Service organisation and commissioning</li> </ul>
<b>Stakeholder involvement</b>	
<b>The GDG</b>	A multidisciplinary group representing physicians working with patients with PDOC; allied health professionals; commissioners; advocacy services; legal professionals; academic researchers with expertise in family experience; and patient/family representatives.
<b>Consultation</b>	Updates to these guidelines lean substantially on the guidance for <i>Clinically-assisted nutrition and hydration in adults who lack the capacity to consent in England and Wales</i> , which were published jointly by the British Medical Association and RCP in December 2018 and endorsed by the General Medical Council. That guidance was based on very wide consultation with a broad range of professionals and other stakeholder organisations.
<b>Funding</b>	Central administrative support and the cost of meetings was provided by the RCP.
<b>Editorial independence</b>	All members of the GDG declared any conflicts of interest.
<b>Rigour of development</b>	
<b>Evidence gathering:</b>	

## Methodology

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<b>Review process</b>	The evidence from the literature reviews was evaluated by members of the GDG.
<b>Links between evidence and recommendations</b>	The NSF typology was used to formulate grades of recommendation for the concise guidance (see Appendix 1 for details).
<b>Piloting and peer review</b>	The penultimate draft of the guidelines was reviewed by the various endorsing and supporting stakeholder organisations. Feedback received was considered while preparing the final draft, which was then approved by the RCP Council.
<b>Applicability and implementation:</b>	
<b>Tools for application</b>	A number of electronic annex documents are included which provide more specific operational advice about implementation of the recommendations; tools and checklists; and access to other useful functional measures for patients emerging from a prolonged disorder of consciousness. The annexes are available at <a href="http://www.rcplondon.ac.uk/pdoc">www.rcplondon.ac.uk/pdoc</a> .
<b>Plans for update</b>	The guidelines will be reviewed in 2025

CANH = clinically assisted nutrition and hydration; GDG = Guideline Development Group; MCS = minimally conscious state; NSF = National Service Framework; PDOC = prolonged disorders of consciousness; RCP = Royal College of Physicians; VS = vegetative state

## Foreword

Patients who remain in a vegetative or minimally conscious state following profound brain injury present a complex array of clinical and ethical challenges to those who care for them. Diagnosis is often difficult and may change over time as patients recover awareness, requiring repeated skilled assessment by clinicians with specific experience in this area. Furthermore, by definition, these individuals lack the mental capacity to make decisions regarding their own care and treatment, so (unless there is a valid and applicable advance decision) these have to be made for them on the basis of their best interests.

Exactly where those interests lie will vary from patient to patient. There are widely differing views, both among clinicians and the general public, about issues such as where patients are cared for; the appropriate use of life-sustaining treatments and management at the end of life. Family members and the treating team may sometimes come into conflict in their respective efforts to do what they believe to be right for the patient. Usually these conflicts can be resolved through open and frank discussion or mediation but, on occasion, they may require judgment from the court.

These guidelines update the previous RCP's *Prolonged disorders of consciousness, National clinical guidelines* (2013) particularly in relation to recent developments in assessment and management: and with respect to recent changes in the law governing procedures for the withdrawal of clinically assisted nutrition and hydration. They attempt to lay out for clinicians, service providers and commissioners what constitutes best practice within the existing legal framework, to enable them to fulfil their various responsibilities to the patient and their family.

The guidelines address some highly emotive and topical areas in which there is currently a dearth of formal research-based evidence to guide practice. The Guideline Development Group was deliberately chosen to represent a wide range of opinion. Some areas provoked rigorous and prolonged discussion, but we have endeavoured to provide a balanced view, based on the best evidence available at the current time.

Further systematic longitudinal data collection is urgently required in this area and the group has recommended the development of a national register and dataset to facilitate this. This recommendation is strongly endorsed by the RCP Council.

In this rapidly changing field the recommendations are likely to need updating as new evidence emerges and as international consensus develops. In the meantime, we have aimed to provide a practical and useful source of advice for clinicians who work with this complex group of patients.

**Prof Lynne Turner-Stokes MBE**  
**Prof Derick Wade**  
**Prof Diane Playford**  
**Co-chairs of the Guideline Development Group**

## Executive summary

These guidelines update the previous RCP's *Prolonged disorders of consciousness, National clinical guidelines* (2013) and aim to achieve a more consistent approach to diagnosis and management of patients with prolonged disorders of consciousness (PDOC), including vegetative (VS) and minimally conscious states (MCS).

The guidelines are prepared in six sections covering the following areas:

### Section 1 provides definitions and criteria for diagnosis of vegetative and minimally conscious states

- > It examines the factors that affect prognosis for recovery and sets out the conditions under which VS and MCS may be classified as 'continuing', 'chronic' or 'permanent'.
- > It also describes operational parameters for demonstrating reliable and consistent responses to indicate emergence from MCS into full consciousness.

### Section 2 describes the clinical assessment, diagnosis and monitoring of patients with PDOC

- > It recommends the use of structured clinical assessment tools alongside detailed clinical assessment, presenting three key instruments along with their various advantages and disadvantages.
- > It describes the use of these tools for long-term evaluation and monitoring, laying out key timepoints for assessment and diagnosis to inform clinical and 'best interests' decision-making.
- > It also explores the role of imaging and electrophysiology, and reviews the evidence for interventional programmes, including medication and sensory stimulation.
- > Finally, it offers some practical techniques for screening for symptoms, such as pain and depression.

### Section 3 describes the care pathway from acute to longer-term management

- > It sets out the general principles and describes the stages of care from management in the acute setting, through specialist neurorehabilitation, to slow-stream placement and ultimately long-term care.
- > It also provides guidance on providing support for families as they confront the challenges of catastrophic brain injury.

### Section 4 sets out the ethical and medico-legal framework for decision-making

- > It sets out the legal background and evolving case law in PDOC.
- > It describes the Mental Capacity Act (MCA) 2005 and lays out the provisions of the act to support decision-making for persons who lack capacity – including the Advance Decision to Refuse Treatment (ADRT) and the roles of a Health and Welfare Lasting Power of Attorney (LPA), a court-appointed Welfare Deputy and an Independent Mental Capacity Advocate (IMCA), as well as the roles of the family and treating team.
- > It highlights the responsibility of clinicians to comply with the MCA 2005 to ensure that any intervention (including life-sustaining treatment) is given in the patient's best interests and in line with their likely wishes.

- > It describes the framework for proportionate external review to replace scrutiny by the court for withdrawal of clinically assisted nutrition and hydration (CANH).
- > It describes the situations in which a court application may still be necessary.
- > It highlights the responsibilities of health professionals who may have a conscientious objection.

### **Section 5 provides practical advice on decision-making regarding starting or continuing life-sustaining treatments (including CANH) and also the practical management of end-of-life care**

- > It describes the range of life-sustaining treatments that need to be considered, including escalation of urgent or unplanned interventions in case of medical instability, and also elective / longer-term interventions.
- > It addresses the challenges of decision-making for ceiling of treatment and withdrawal of life-sustaining treatment, and provides advice for informing families and normalising discussion.
- > It recommends a comprehensive approach to Treatment escalation planning to ensure that all the relevant forms of life-sustaining treatment are considered and documented from an appropriately early stage in the pathway and kept under review.
- > It describes the process required to document lack of capacity and to establish the patient's best interests, and to obtain information about their likely wishes – also setting out practical arrangements for *best interests* decision-making meetings and topics for discussion.
- > This section also addresses care of the patient dying in PDOC and the particular challenges for palliative care in the context of elective withdrawal of life-sustaining treatment, including CANH.
- > It describes the principles of palliative care and presents some questions frequently asked by families, suggesting some ways of answering them.
- > It addresses some of the particular challenges for end-of-life care in this context and addresses the types of setting in which this may be offered.
- > It also sets out a detailed regimen for staged escalation of sedation and analgesia, using either a subcutaneous or intravenous route of administration, to manage any symptoms and signs of physiological distress in the terminal stages.

### **Section 6 describes commissioning and organisation of services for patients in PDOC**

- > It proposes a network model in which highly skilled specialist staff in designated inpatient specialised services also provide outreach support to local teams in slow-stream rehabilitation and long-term care services.
- > It emphasises the requirement for a collaborative approach from both palliative care and neurorehabilitation teams in neuropalliative and end-of-life care.

Finally, this section also addresses the requirement for further research and development to improve our understanding of PDOC including:

- > the role of functional imaging and electrophysiology
- > longitudinal evaluation through systematic cohort analyses to determine prognosis and survival and to identify the factors that predict recovery
- > economic evaluation to identify cost-effective models of care

- > optimisation of palliative care regimens to manage end-of-life care within different care settings.

It recommends the establishment of a national register and agreed minimum dataset for the collection of a national cohort of longitudinal outcome data for patients with PDOC to be incorporated within the UK Rehabilitation Outcomes Collaborative (UKROC) national clinical database.

The guidelines are accompanied by a set of electronic annexes (listed in Appendix 2 and available online at [www.rcplondon.ac.uk/pdoc](http://www.rcplondon.ac.uk/pdoc)) that provide further detail and practical advice to assist clinicians caring for patients in PDOC, as well as offering a guide for family and friends about their role in decision-making.

## Section 1

# Defining criteria and terminology

### 1.1 Introduction

Disorders of consciousness include:

- > coma (usually acute and short term)
- > prolonged disorders of consciousness (PDOC) (unconscious for more than 4 weeks)
  - vegetative state (VS)
  - minimally conscious state (MCS).

Disordered consciousness can occur in two main contexts:

- a prolonged disorder of consciousness (PDOC) following sudden onset acquired brain injury
  - from which the patient may or may not regain consciousness
- b terminal decline of consciousness (TDOC) towards the end of life in patients with progressive degenerative brain damage (for example due to dementia, Parkinson's disease or multiple strokes).

Figure 1.1 illustrates some possible trajectories for patients with disordered consciousness in the context of sudden onset and progressive or degenerative brain injury.

Patients in either category may have either no or limited awareness of themselves or their environment. The important distinctions, however, are *prognosis and certainty*, both in terms of the potential for improvement and the length of time for which the patient may live.

- > In sudden onset PDOC, many are relatively young and fit, and may live for a decade or more. In the early stages, some patients may have potential for recovery of a meaningful quality of life.
- > In TDOC survival times are relatively short (often less than 1–2 years) and there is no potential for improvement.

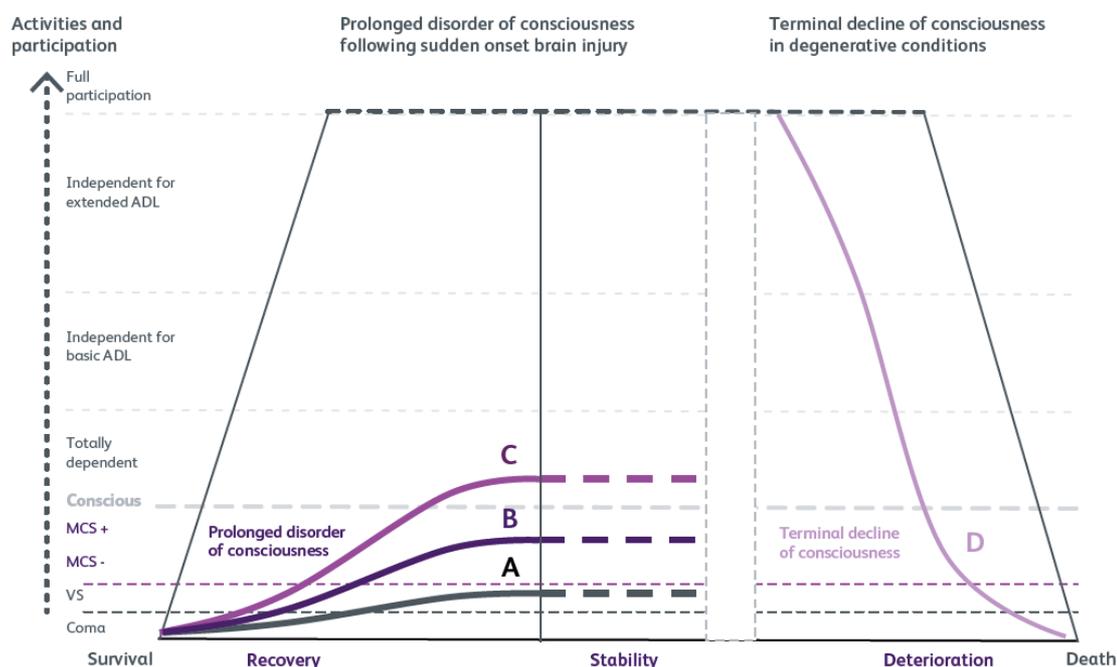
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*These guidelines concern the diagnosis, management and lifelong (including end-of-life) care of adults (aged 16 and over) who have PDOC, lasting for more than 4 weeks following sudden onset profound acquired brain injury of any cause.*

---

The major causes are listed in Table 1.1

**Fig 1.1 Schematic diagram of some possible trajectories of disordered consciousness lasting >4 weeks**



Following severe brain injury, many patients progress through stages of coma, VS and MCS as they emerge into a state of full awareness and start to recover independence. Some, however, will remain in a vegetative or minimally conscious state for the rest of their lives.

The left side of this diagram illustrates three possible pathways for patients in PDOC following sudden onset brain injury. Patients A, B and C all present in coma following sudden onset prolonged disorder of consciousness (PDOC). Patient A remains in VS; patient B plateaus in MCS, while patient C emerges into consciousness but remains totally dependent. On the right side of the diagram, Patient D has TDOC as a result of progressive degenerative disease.

ADL = activities of daily living; MSC = minimally conscious state; PDOC = prolonged disorders of consciousness; TDOC = terminal decline of consciousness; VS = vegetative state

**Table 1.1 Common causes of profound brain injury resulting in PDOC**

Aetiology	Examples
<b>Trauma</b>	Direct impact, or diffuse axonal injury resulting from rapid deceleration
<b>Vascular event</b>	Catastrophic intracerebral or subarachnoid haemorrhage, and other strokes
<b>Hypoxic or hypoperfusion</b>	Due to cardiorespiratory arrest or profound hypovolaemia
<b>Infection or inflammation</b>	Encephalitis, vasculitis, meningitis
<b>Toxic or metabolic</b>	Drug or alcohol poisoning, severe hypoglycaemia

The causative illnesses can occur at any age. Some patients will be previously healthy and fit with decades of life ahead of them. Others will have frailty or comorbidities (multiple health conditions) that would naturally shorten their life expectancy irrespective of the brain injury.<sup>4</sup>

The advice in these guidelines is primarily focused on the needs of patients who may be expected to have many years of life ahead of them if they continue to receive full clinical treatment and care. While some of the key principles may have relevance for other patient groups, they should be interpreted with common sense when applied in the context of a naturally shortened life expectancy due to other conditions.

Older patients who have suffered large strokes or subdural bleeds may present in a PDOC state, but their life expectancy may be significantly limited by multiple health conditions and/or frailty, such that their trajectory is more consistent with those in a TDOC state. Even those individuals who were fit and active pre-injury are likely to become rapidly frailer as a result of the injury, which will impact on life expectancy. Decisions about how to treat these patients need to be made on an individual basis by the treating team – it may not be appropriate to commit them to the full range of PDOC assessments that might be used for a younger person with a better prognosis. At the same time, they should have timely access to relevant expertise and assessments, and age alone should not be the determining factor.

### Definition of ‘family’

Awareness may vary in patients with PDOC, but even if the patient has little awareness of their situation, their families and close friends often experience very severe distress requiring active support in their own right.<sup>3</sup> They may need help to come to terms with the radical changes in their lives that result from a loved one’s catastrophic brain injury. The children of patients with PDOC often have particular needs for support. Therefore these guidelines address the needs of the family, as well as those of the patient.

Family and friends may be actively involved in the assessment and ongoing care of the patient. Importantly, they also play a key role in the clinical decision-making process as they provide important insights into the character, beliefs and likely wishes of the patient (see also Sections 3–5). The provision of timely information, education and support for families, and consultation with them, is therefore a critical factor for successful management and appropriate decision-making regarding care and treatment.<sup>2</sup>

The term ‘family’ in this guidance is intended to be inclusive and should not be read as restricted by legal ties or blood relations. It may potentially include anyone who has a sufficiently close relationship with the patient to be actively concerned with their management and wellbeing – and as such has a legitimate interest that permits disclosure of clinical information as a part of providing support and *best interests* decision-making (see Section 4). It is important to be aware, however, that patients’ relatives may have a more restricted understanding of ‘family’. Clinicians should therefore be alert to the need to include others who were important to the patient, and whom the patient him/herself might wish to be involved in discussions about their care and treatment.

## 1.2 Definitions and characteristics

Consciousness is an ambiguous term, encompassing both wakefulness and awareness.<sup>5</sup>

- > 'Wakefulness' is a state in which the eyes are open and there is a degree of motor arousal; it contrasts with sleep – a state of eye closure and motor quiescence.
- > 'Awareness' is the ability to have, and the having of, experience of any kind.

There is no simple single clinical sign or laboratory test of awareness. Its presence must be deduced from a range of behaviours which indicate that an individual can perceive self and surroundings, frame intentions, and interact with others.

### Terminology

The term 'vegetative state' was originally coined by Jennet and Plum in 1972.<sup>6</sup> In recent years, there has been a growing sense of discomfort in referring to patients as 'vegetative' in the belief that it is synonymous with 'being a vegetable'. This is not the case. The origins of the term date back to Aristotle who described the various faculties of the soul, noting that plants and animals both have the 'vegetative' faculty to live and grow, but only animals have the higher faculties for sensation, movement and thought. A person in vegetative state can live and grow, but cannot sense or perceive, and the question for prognosis is whether there is a realistic possibility of return to any semblance of 'cognitive' or 'sapient' state.<sup>7</sup>

The Guideline Development Group (GDG) considered various alternative terminologies:

- > Umbrella terms:
  - 'Low awareness state' has been used as a generic term for VS/MCS, until a more precise categorisation can be determined. The term is problematic as some patients will be completely unaware.
  - The 1995 US Task Force used the term 'disorder of consciousness' (DOC) as some of their guidance refers to the period within 4 weeks of brain injury, before disordered consciousness may be said to be 'prolonged'.
- > The European Task Force on Disorders of Consciousness has proposed the term 'unresponsive wakefulness syndrome' (UWS),<sup>8</sup> to replace that of 'vegetative state'. However, the term remains problematic.
  - The Task Force deliberately avoided the term 'unawareness', acknowledging that detailed evaluation will reveal a certain level of awareness in some patients.
  - The term 'unresponsive' is problematic, however, as many patients show some level of response, albeit at reflex level.

The recent US *Practice Guidelines Update: Disorders of Consciousness* from the American Academy of Neurology (AAN) published in September 2018<sup>9</sup> takes a middle line, referring to VS/UWS which serves only to combine all of the above weaknesses.

The RCP GDG for these updated UK guidelines has considered the issue of terminology carefully. We also debated whether it was useful to have any term to separate the different levels of PDOC. In the past, clinicians have often been over-preoccupied with the distinction between VS and MCS, which has partly been fuelled by the emphasis put on this by the courts.

From a legal perspective, that distinction is no longer critical (see [Section 4](#)). Nevertheless, the GDG agreed to retain the terms 'vegetative state' (VS) and 'minimally conscious state' (MCS) at the present time, as there are clear definitions for them and both the public and commissioners generally know what they mean. In addition, they still have relevance for epidemiological research and the interpretation of research findings, for example in relation to prognosis and outcome.

However, the GDG recommends that the terms ‘VS’ and ‘MCS’ should be used only in the context of PDOC following sudden onset acquired brain injury (which is the context in which they are predominantly used in the research literature on outcomes). They should not be used in relation to other conditions, such as TDOC, as this will confound the data on prognosis and outcome.

Within these RCP guidelines we recommend that:

- > The term ‘**prolonged disorder of consciousness**’ (PDOC) should be used to describe any disorder of consciousness that has continued for at least 4 weeks following sudden onset brain injury.
- > The terms ‘**VS**’ and ‘**MCS**’ should only be applied after a formal diagnosis of the level of consciousness has been made through careful serial assessment by appropriately trained staff (see [Section 2 – Assessment, diagnosis and monitoring](#)).
- > We accept that some families dislike the term ‘vegetative state’ – although others report that it is helpful, (especially at the end of life) to understand that the patient is not aware and not suffering.
- > If and when a more acceptable, internationally agreed term emerges, this will be adopted in future iterations of these guidelines.
- > For the purposes of this guideline, we use the definitions shown in Table 1.2.

All ‘disorders of consciousness’ are quite distinct from ‘locked-in syndrome’ or ‘brainstem death’.

- > The **locked-in syndrome** (helpfully described by journalist Jean-Dominique Bauby in his book, *The Diving Bell and the Butterfly*<sup>11</sup>) usually results from brainstem pathology which disrupts the voluntary control of movement without abolishing either wakefulness or awareness. Patients who are ‘locked in’ are substantially paralysed but fully conscious, and can usually communicate using movements of the eyes or eyelids.
- > **Brainstem death** implies the loss of all brainstem functions, as confirmed by the absence of brainstem reflexes (pupillary, corneal, oculovestibular and cough) and spontaneous respiratory effort in response to rising carbon dioxide levels so requiring ventilator support.

Patients with brainstem death may be maintained for short periods on artificial ventilation, to allow clinical and *best interests* decision-making, or support organ donation, but will inevitably cease to maintain physiological function within a relatively short period after withdrawal of ventilator support. By contrast, patients in VS/MCS may require a tracheostomy, but typically maintain their own cardiac output and respiration, and so may survive for months (or in some cases many years) without cardiorespiratory support.

Table 1.2 Definitions of disorders of consciousness

<p><b>Coma</b> (absent wakefulness and absent awareness)</p>	<p>A state of unrousable unresponsiveness, lasting more than 6 hours in which a person:</p> <ul style="list-style-type: none"> <li>&gt; is unconscious and cannot be awakened</li> <li>&gt; fails to respond normally to painful stimuli, light or sound</li> <li>&gt; lacks a normal sleep–wake cycle</li> <li>&gt; does not initiate voluntary actions.</li> </ul>
<p><b>VS</b> (wakefulness with absent awareness)</p>	<p>A state of wakefulness without awareness in which there is preserved capacity for spontaneous or stimulus-induced arousal – evidenced by sleep–wake cycles and a range of reflexive and spontaneous behaviours.</p> <p>VS is characterised by absence of behavioural evidence for self or environmental awareness.</p>
<p><b>MCS</b> (wakefulness with minimal awareness)</p>	<p>A state of severely altered consciousness in which minimal but clearly discernible behavioural evidence of self or environmental awareness is demonstrated.<sup>10</sup></p> <p>MCS is characterised by <i>inconsistent, but reproducible</i>, responses above the level of spontaneous or reflexive behaviour, which indicate some degree of interaction with their surroundings.</p>

MCS = minimally conscious state; VS = vegetative state

Although these various states are reasonably easily distinguished, many clinical teams have little experience of diagnosing the nature of PDOC. Therefore, it is important to involve clinicians who are familiar with assessment of people with complex cognitive and/or communication impairments after profound brain injury, and who have specific experience and expertise in the assessment of PDOC.

### 1.3 Sub-classification of PDOC

It is now increasingly recognised that PDOC form a continuous spectrum of awareness and interaction rather than a set of distinct entities. Moreover, consciousness may fluctuate over time so that the categorisation of VS and MCS becomes ‘blurred’ at the borders and this accounts for much of the widely publicised ‘misdiagnosis’ of these states.<sup>12</sup>

In 2013, when the previous version of these guidelines was published, the distinction between VS and MCS was still critical to any legal judgment relating to the withdrawal of CANH, so much attention was given to the differential diagnosis of these states. With recent changes in the law, there is no longer any legal imperative to categorise a patient into VS or MCS. However, from a clinical perspective, it is still important to try to determine the extent to which the patient is aware of themselves and their environment. This will help to evaluate their balance of experiences both positive (eg interaction with family members and favourite things) and negative (eg pain, distress, low mood etc).

In addition, we know that the more rapidly patients move through the different levels of PDOC in the early stages, the more likely they are to recover consciousness and achieve better functional outcomes. An internationally transferable classification of different levels of PDOC provides a common language and enables us, not only to describe a patient's progress, but to learn valuable lessons from international experience on prognosis and outcomes, and also to contribute our own future research to that shared knowledge base. The next sections set out the criteria for sub-classification of the different levels of PDOC, which are summarised in Fig 1.2.

### 1.4 Preconditions

Before making a diagnosis of VS or MCS, the preconditions shown in Table 1.3 must apply.

**Table 1.3 Preconditions for diagnosis of VS or MCS**

Precondition	Detail
<b>1 Cause of condition known</b>	The cause of the condition should be established as far as is possible. Eg injury, degenerative conditions, metabolic/infective disorders. (Occasionally a precise cause cannot be identified).
<b>2 Reversible causes excluded</b>	The possibility of reversible causes must be excluded, including: <ul style="list-style-type: none"><li>&gt; the influence of drugs</li><li>&gt; metabolic causes</li><li>&gt; treatable structural causes, eg collection of blood / hydrocephalus / syndrome of the trephined.</li></ul>
<b>3 Careful assessment</b>	The patient should be examined: <ul style="list-style-type: none"><li>&gt; by trained assessor(s) experienced in the management of PDOC</li><li>&gt; under appropriate conditions (positioning, environment etc)</li><li>&gt; using validated tests, in a series of observations over an appropriate period of time. (See <a href="#">Section 2</a> for further detail on assessment).</li></ul>

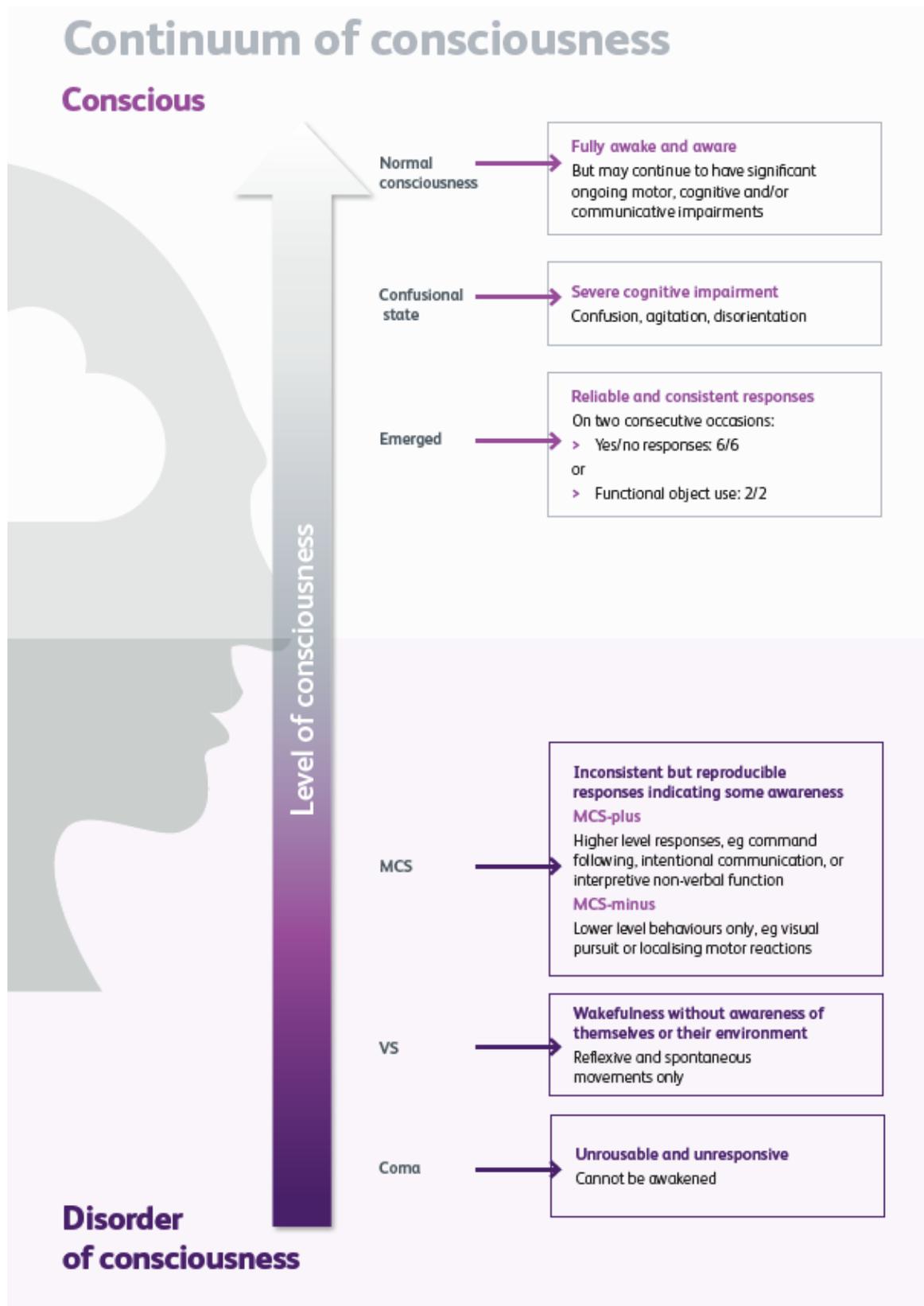
MCS = minimally conscious state; PDOC = prolonged disorders of consciousness; VS = vegetative state

#### Essential features of VS

Patients in VS have spontaneous respiration and circulation and their eyes are open spontaneously for periods of the day, giving the appearance of a sleep–wake cycle.

In addition, they may exhibit a range of spontaneous movements and/or reflex responses.

Fig 1.2 Prolonged disorders of consciousness – UK descriptors along the continuum of consciousness



However, there is no evidence of:

- 1 awareness of self or environment or the ability to interact with others

- 2 sustained purposeful or voluntary behaviours, either spontaneously or in response to visual, auditory, tactile or noxious stimuli
- 3 language, comprehension or meaningful expression.

Box 1.1 sets out the typical features that are compatible with a diagnosis of VS.

### Box 1.1 Typical behaviours that may occur that occur in VS

#### Spontaneous movements

The following may occur for no discernible reason:

- > chewing, teeth grinding, tongue pumping
- > roving eye movements
- > purposeless movements of limbs and/or trunk
- > facial movements – such as smiles or grimaces
- > shedding tears
- > grunting or groaning sounds.

#### Reflexive movements

The following reflexes are usually preserved:

- > brainstem reflexes
  - (pupillary, oculo-cephalic (doll's eye), oculo-vestibular (caloric))
- > corneal reflex
- > reflexive oral/facial reflexes
  - (eg gag, saliva swallowing, tongue thrust, bite reflex, rooting, lip pursing)
- > grasp reflex.

Various stimuli (eg noxious or noise) may produce a generalised arousal response, with:

- > quickening of respiration,
- > grimacing or other oro-facial dyskinesia, non-localising limb movements (eg extension, flexor or withdrawal reflexes).

Eyes may turn fleetingly to:

- > follow a moving object or towards a loud sound,
- > fixate on a target
- > react to visual menace.

But they do not usually follow a moving target for more than a second or two.

### Atypical but compatible features of VS

Patients may also show isolated fragments of behaviour, such as the utterance of a single inappropriate word, or spontaneous stereotyped movements such as fiddling, scratching or repeatedly rubbing the same areas of their body. These features appear to reflect the survival of 'islands' of cortex, which are no longer part of the coherent thalamocortical system required to generate awareness. They should prompt careful reassessment of the diagnosis, but they do not in themselves negate the diagnosis of the VS.

### Incompatible features

Features that are incompatible with VS include:

- > evidence of discriminative perception
- > purposeful actions, including reproducible localising responses
- > anticipatory actions
- > communicative acts.

For example, a smile specifically in response to the arrival of a friend or relative would be incompatible with VS, whereas a spontaneous smile would be compatible. Similarly, an attempt to reach out for an object or the appropriate use of language would indicate the recovery of some awareness of their surroundings, even though this may be very limited, and would be incompatible with VS.

### 1.5 Criteria for diagnosis of MCS

The definition of a MCS was first published by the Aspen Neurobehavioral Conference Workgroup in 2002,<sup>13</sup> based on the requirement for at least one clear-cut behavioural sign of consciousness, indicating that patients retain at least some capacity for cognitive processing.

To make the diagnosis of MCS, limited but clearly discernible evidence of self or environmental awareness must be demonstrated on an inconsistent, but reproducible or sustained basis, by one or more of the behaviours listed in Box 1.2.<sup>10</sup>

The reproducibility of such evidence is affected by the consistency and complexity of the behavioural response:<sup>10</sup>

- > Extended assessment may be required to determine whether a simple response (eg a finger movement or eye blink) that is observed infrequently is occurring in response to a specific environmental event (eg a command to move fingers or blink eyes) or on a coincidental basis.
- > In contrast, a few observations of a complex response (eg intelligible verbalisation) may be sufficient to determine the presence of awareness.

### Subcategorisation of MCS

MCS encompasses a broad spectrum of responsiveness from a very low level (where patients start to show evidence of non-reflexive movements) to a higher level of meaningful interaction, albeit still inconsistent.

Bruno and colleagues (2011) have recommended a division of MCS into 'plus' and 'minus' subcategories based on the level of complexity of observed behavioural response.<sup>14</sup> MCS-minus patients show only non-reflexive localising and pursuit movements while MCS-plus patients show more complex behaviours. There is at least preliminary evidence of differential functional anatomy in these groups.<sup>15, 16</sup>

**Box 1.2 Behaviours compatible with MCS**

- a Following simple commands.
- b Gestural or verbal 'yes/no' responses (regardless of inaccuracy).
- c Intelligible verbalisation (accepting inaccuracy due specific speech or language deficits)
- d Purposeful or discriminating behaviour, including movements or affective behaviours:
  - that occur in contingent relation to relevant environmental stimuli
  - that are not due to reflexive or spontaneous activity.

Any of the following examples provide sufficient evidence for a behavioural response that is only explicable through some awareness being present:

- a Episodes of crying, smiling, or laughter in response to linguistic or visual content of emotional (but not neutral) topics or stimuli
- b Vocalisation or gestures in direct response to the linguistic content of comments or questions
- c Reaching for objects in a manner that demonstrates a clear relationship between object location and direction of reach
- d Touching or holding objects in a manner that accommodates the size and shape of the object
- e Sustained pursuit eye movement or sustained fixation that occurs in direct response to moving or salient stimuli
- f Other localising or discriminating behaviours that constitute:
  - movement towards a perceived object or
  - differential responses to different objects or people.

Further clinical characterisation<sup>17</sup> has shown that the most frequent signs of consciousness in MCS-minus patients are:

- > visual fixation and pursuit,
- > automatic but localising motor reactions (eg targeted scratching, pulling the bed sheet)
- > localisation to noxious stimulation.<sup>17</sup>

MCS-plus patients show, in addition, some evidence of language processing / communication such as following simple commands, intelligible verbalisation or intentional communication, albeit still inconsistently.<sup>14, 18</sup> Lack of language function should be interpreted with caution in patients who have specific evidence of dominant hemisphere damage and who may be aphasic, but in that case there should still be clear evidence of interpretative non-verbal function, such as reasoning / problem-solving. Table 1.4 lists behaviours that are compatible with different subcategories of MCS.

## 1.6 Emergence from minimally conscious states

The hallmark of a minimally conscious state is that the interactions and behavioural responses are 'inconsistent but reproducible'.

Emergence from MCS is signalled by the recovery of *reliable and consistent* responses. However, the upper border of MCS is hard to define.

Table 1.4 Behaviours compatible with MCS-minus and MCS-plus

	Features of MCS-minus	Additional features MCS-plus
<b>Localising interactions</b>		
<b>Visual</b>	>	Pursuit, eg following a moving object with their eyes
<b>Auditory</b>	>	Pursuit, eg turning eye or head towards a loud sound or familiar voice
<b>Motor</b>	>	Localising motor reactions, eg to noxious stimuli, holding of objects in an appropriate grip
	>	Targeted purposeful movements, eg scratching or picking at objects
<b>Communication and language processing</b>		
<b>Comprehension</b>	-	> Following simple commands appropriately
<b>Expression</b>	-	> Yes/no response (albeit inconsistent)
		> Intelligible verbalisation appropriate to the situation (through speech or writing)
		> Intentional non-verbal communication, eg with gesture
<b>Cognitive</b>	-	> Copying, matching, choosing objects
		> Evidence of reasoning / problem solving (either verbal or non-verbal)

The US Aspen Work Group<sup>13</sup> proposed that emergence from MCS is characterised by *reliable and consistent* demonstration of one or both of the following:

- > functional interactive communication – which may occur through verbalisation, writing, yes/no signals or use of augmentative communication devices
- > functional use of objects – behavioural evidence of discrimination between at least two different objects.

The inclusion of functional use of objects enabled non-verbal (aphasic) patients to demonstrate consistent behaviours indicating full consciousness. However, the Aspen Group defined this rather vaguely as ‘generally appropriate use of objects’. A proportion of patients in PDOC will fiddle with objects in a generally appropriate way, such as holding a pen and producing meaningless scribble, but without any further evidence of intelligent application. This represents a considerably lower level cognitive engagement than producing language or responding appropriately and consistently to questions.

The 2018 US guidelines do not define criteria for emergence and so have not addressed this issue. After due consideration, the UK GDG recommended a slightly tighter definition of functional use of objects that requires evidence of intelligent thought – so, for example, using the pen to form letters or recognisable shapes. In addition, for the avoidance of doubt, if emergence is to be judged on the basis of reliable and consistent demonstration of functional interactive communication, the answers do need to be correct.

This still leaves unanswered the duration of awareness experienced. Showing evidence of language or functional use of objects for just a few minutes is very different from doing this consistently over many hours a day. Where there is variability of response, this still amounts to inconsistency over time. For meaningful emergence into consciousness, the responses should be sustainable. Patients should be able to demonstrate consistency for all (or most of) the time when they are awake and with more than one person.

### Operational parameters

To facilitate consistent reporting of findings among clinicians and investigators working with patients in MCS, the GDG proposed a brief set of operational parameters to be used for demonstrating the reliability and consistency of responses.

The GDG accepted the concern that patients with severe brain injury may have difficulty in answering yes/no questions accurately due to specific language deficits (such as aphasia),<sup>19, 20</sup> and similarly their ability to carry out functional tasks may be limited by the absence of motor function or apraxia. In addition, there is evidence that familiar stimuli in an emotionally enriched context are more likely to elicit a response.<sup>21, 22</sup> Therefore we have recommended a slight expansion of the operational parameters, as summarised in Table 1.5. We also recommend the use of standardised sets of biographical and situational questions that are suitable for translation into different languages.

More detailed rationale and guidance on the operational parameters and their application is given in electronic Annex 1a at [www.rcplondon.ac.uk/pdoc](http://www.rcplondon.ac.uk/pdoc).

We recognise that these additions may not go far enough for some clinicians. However, the GDG considers that patients who lack the ability to interact in a consistent and meaningful way remain vulnerable and in need of specialist care and support. For those whose interactive inability prevents the accurate determination of their level of awareness, the risk of lowering the bar for emergence from MCS could result in disadvantage if they then fail to qualify for the level of care and services for patients in PDOC detailed later in this report.

If and when a patient emerges from MCS, the operational parameters used to demonstrate this (as given in Table 1.4) should be formally recorded in the notes, dated and signed by the responsible clinician.

**Table 1.5 Operational parameters for demonstrating response reliability and consistency**

<b>Patients should demonstrate a consistent response in at least one of the following types and should do so whenever awake (eyes open) and presented with the situation:</b>	
<b>Functional use of objects</b>	Intelligent use of at least two different objects on two consecutive evaluations (with or without instruction), eg writes or draws using a pen or pencil and uses a comb or hairbrush to brush hair <sup>a</sup>
<b>Consistent discriminatory choice making</b>	Consistently indicates the correct choice from two pictures on 6/6 trials on two consecutive occasions. (Use at least three different picture pairs)
<b>Functional interactive communication</b>	
<b>Evidence of awareness of self</b>	Gives correct yes/no responses to 6/6 autobiographical questions on two consecutive evaluations <sup>b</sup>
<b>Evidence of awareness of their environment</b>	Gives correct yes/no responses to 6/6 basic situational questions on two consecutive evaluations

<sup>a</sup> Functional use requires evidence of cognitive engagement such as actually writing words or drawing recognisable shapes, rather than meaningless scribbling

<sup>b</sup> NB When assessing awareness using forced choice questions, the presentation must be counterbalanced; half the questions correct and half incorrect. Visual information should be presented in both left and right visual fields on each trial to prevent response bias<sup>23</sup>

## 1.7 Prognosis for survival and improvement of awareness

Words used in relation to a patient’s future are often misinterpreted or interpreted differently by clinicians, families and non-healthcare professionals.

- > The term ‘recovery’ should be avoided because it may refer to change for the better (improvement) or to a ‘return to pre-injury status’.
- > Patients who have been in PDOC for more than a month or two will inevitably have significant permanent physical and cognitive deficits.
- > Improvement in ‘awareness’ – or indeed even in ‘functional status’ – should not necessarily be equated with improvement in the patient’s quality of life, unless there is a clear understanding of what ‘quality of life’ meant to that individual person.
- > For many patients, being more aware of their situation (and its associated limitations) can mean being in a worse condition for them, rather than a better one.

The GDG therefore recommends that the term ‘improvement’ should be accompanied by a clear statement of the context in which that is being judged:

- > Improvement in awareness, in functional status, or indeed any other parameter?
- > How much ‘improvement’ has been seen to date?
- > What further improvement is expected, over what time?
- > How certain is that prognosis?

In the absence of any more positive information about that particular individual and their beliefs, values and wishes, trajectories are better described in terms of changes in the

parameter, rather than any judgement about that likely impact on the individual's circumstances and quality of life.

The term 'prognosis' is also ambiguous as it is often used indiscriminately to cover both *prognosis for improvement* and *life expectancy*. These should be separated:

- > Prognosis for improvement in awareness or function is affected by a range of factors including the type, severity and the time since onset of the brain injury, the level of consciousness (VS/MCS), and any trajectory of change.
- > Life expectancy will depend to some extent on recovery but (given that we all have a finite life span) is very substantially dependent on age and the presence of other comorbidities / health conditions.

The AAN guidelines provide a detailed systematic review of the available literature on prognosis. Unfortunately, it is confounded by a lack of systematic longitudinal data collection and different definitions of the term 'recovery', which are variously used to denote:

- > return to functional independence
- > recovery of consciousness
- > or simply progression from one level to the next (ie from VS to MCS, or MCS to full consciousness).

In the UK, the focus for prognostication has now shifted from the recovery of consciousness or function to whether the patient could recover a quality of life that they themselves would value (see [Section 4](#)), but as yet there is no direct literature on outcomes related to quality of life, or indeed important domains such as ability to communicate and interact socially, level of functional autonomy, or levels of 'happiness' or pain and distress.

Taken overall, the evidence from the US literature suggests that for patients admitted to rehabilitation with disordered consciousness approximately two-thirds regained full consciousness, and one-quarter emerged from post-traumatic amnesia.<sup>24</sup> Studies that track functional outcome beyond 1 year suggest that up to 20% will eventually regain functional independence and up to 10% will get back to work or education, but the majority of these will have transitioned to MCS before 6 months.<sup>25-27</sup>

These figures need to be interpreted with caution in the UK context. In the US, only one-fifth of patients with DOC get into rehabilitation, but those who do may be transferred within just a few days of injury. Many of these patients will be on a very different trajectory for recovery from the patients presenting to PDOC services in the UK – the majority of who will have already been in PDOC for several weeks, if not months, and so likely to have a poorer outcome.

Nevertheless, we know that some will emerge and recover a degree of independence and autonomy, so the challenge lies in how to identify those patients who are most likely to have either a good or poor outcome, in order both to target rehabilitation efforts and to inform *best interests* decision-making (see Sections 4 and 5).

From the latest reviews<sup>28, 29</sup> we can now identify a number of factors that affect the probability of recovery of consciousness, which include:

- > aetiology – 'traumatic' vs 'non-traumatic' brain injury
- > level of DOC in the first 4 weeks – VS vs MCS-minus vs MCS-plus
- > length of time since injury

- > structural pattern of brain injury
- > severity of disability (as measured by the Disability Rating Scale (DRS) or the Functional Independence Measure (FIM))
- > age
- > medical stability.

Individually, none of the above factors predict outcome with any reasonable level of confidence, and their influence appears to be dynamic and changes over time. With such a diverse and complex range of presentation among PDOC patients, we are very far from being able to use a single algorithm that can predict outcome with any degree of confidence – and in reality it would be naive to expect a simple linear relationship that could support accurate clinical prognostication at individual level.

The following represents reasonable extrapolation from the current state of knowledge:

- > The cause of brain injury is a strong determinant of outcome for both VS and MCS. Patients with non-traumatic (eg anoxic brain or other diffuse) injury have a shorter window for recovery and greater long-term severity of disability than patients with traumatic injury.<sup>30, 31</sup> The presence of medical complications is a further prognostic factor.<sup>32</sup>
- > For both VS and MCS, the likelihood of significant functional improvement diminishes over time,<sup>10, 30</sup> although the prognosis for recovery is more heterogeneous for MCS than for VS.<sup>33, 34</sup>
- > In both VS and MCS there are isolated reports of recovery of consistent consciousness even after many years,<sup>35–37</sup> but these are a rarity, and inevitably those who recover remain profoundly disabled.
- > Any progression is likely to be gradual, and it is likely that patients emerging late from VS/MCS will have shown signs of increasing responsiveness, had these been evaluated systematically over time – as for example was the case of Terry Wallis, a young man who had been thought to be in VS for 19 years. In fact he showed signs of inconsistent gestural communication compatible with MCS from just a few weeks post-injury, but this was before the condition of MCS had been defined.<sup>38</sup>
- > While the prognostic significance of MCS subcategorisation has yet to be fully explored, emerging evidence suggests that MCS-minus aligns more closely with VS and is associated with poorer outcomes, while patients who progress to MCS-plus at an early stage have a greater chance of recovering consciousness.
- > Thus, the trajectory of recovery is increasingly emerging as the most important indication of prognosis for recovery.<sup>18, 26, 39–41</sup> This emphasises the importance of serial testing over time to look for trends towards improved levels of responsiveness.

The US health system typically allows for only a short window of assessment/rehabilitation – often at a very early stage post-injury, even before 4 weeks. In the light of concerns that decisions to withdraw treatment were being made as early as 72 hours post-injury in some patients who might otherwise have made a meaningful recovery, the 2018 US guidelines<sup>42, 43</sup> have recommended a more cautious approach to prognostication, especially in the first 28 days. These UK guidelines, however, do not apply until patients have been in PDOC for at least 4 weeks, and we also have the benefit of NHS care which allows for a considerably longer period of time over which to evaluate and monitor patients. The very different health cultures in which they apply accounts for some of the differences in advice offered by the US and the UK guidelines.

## 1.8 ‘Chronic’ and ‘permanent’ disorders of consciousness

### Previous definitions

Previous guidelines including those from the US<sup>30</sup> and the UK<sup>5</sup> defined two states: ‘persistent’ and ‘permanent’ VS. These both carried the same acronym (PVS), which often led to confusion. To avoid this, the UK National Clinical Guidelines for PDOC 2013<sup>1</sup> therefore replaced the term ‘persistent’ with ‘continuing’, both for VS and MCS.

The longer an individual has remained in PDOC, the less likely they are to regain consciousness.

- > The 1994 US guidelines<sup>30</sup> defined the state of ‘permanent VS’ (12 months after traumatic brain injury and 3 months after non-traumatic injury) as the point after which recovery of consciousness was deemed to be highly improbable.
- > In view of the evidence that a small but significant minority of patients continue to make changes after these timepoints, the 2018 US Guidelines<sup>42, 43</sup> have replaced the term ‘permanent VS’ with ‘chronic VS/UWS’ – again 12 and 3 months respectively after traumatic and non-traumatic brain injury.
- > Neither the 1994 nor the 2018 US guidelines, however, attempt to define conditions under which MCS may be considered either to be ‘chronic’ or ‘permanent’.

The 2013 UK guidelines<sup>1</sup> adopted a broadly similar approach but recommended the more cautious period of 6 months for diagnosis of permanent VS in non-traumatic brain injury. They also advised that MCS may be regarded as permanent between 3 and 5 years post-injury, depending on a number of factors including the general condition of the patient and any other comorbidities, the nature and severity of the injury, the level of responsiveness, and (most importantly) any trajectory of change.

In England, the diagnosis of ‘permanent VS’ had legal importance in 2013, as the criterion that the courts used to determine whether or not it was lawful to withdraw life-sustaining treatment in the form of CANH. This was based on the premise that, if the patient had no positive experience at all, further treatment aimed at prolonging life would be ‘futile’ as it could not possibly bring any benefit to them.

However, more recent case law (*Aintree v James* [2013] UKSC 67, *Briggs v Briggs* [2016] EWCOP 53) has brought a change in focus, the emphasis no longer being on the likelihood of regaining consciousness, but on whether a patient could ever recover a quality of life that they personally would value. *Best interests* discussions are therefore centred on a discussion of the patient’s prior beliefs and values, and the predicted ‘best’ and ‘worst case’ scenario for recovery in terms of regaining ability to function independently, to communicate or interact at any level.<sup>4</sup>

Inevitably there is a level of uncertainty about such predictions, especially in the early stages post-injury, but as time goes on the extent of likely recovery becomes clearer. Although the need to define a permanent state has become redundant so far as the law is concerned, as noted on page 37 it may still be relevant for other areas of clinical management and treatment planning. It may also help to establish realistic expectations for outcome in discussions with family and friends.

The determination of when a patient reaches the stage where it is unlikely that they will regain consciousness is based on a complex set of factors that can only be judged through careful evaluation over time by an experienced clinician, paying particular attention to the trajectory of

change. The definitions provided below should therefore not be taken as fixed points at which to make decisions. They are there to provide a simple ‘rule of thumb’ guide to inform discussions with family members and other clinicians.

### Definitions applied within this set of guidelines

#### ‘Continuing’ VS and MCS

Once detailed assessment has been undertaken, patients may be diagnosed as having:

- > ‘continuing VS’ when they have continued to demonstrate complete absence of behavioural evidence for self or environmental awareness for more than 4 weeks, or
- > ‘continuing MCS’ when they continue to demonstrate inconsistent, but reproducible, interaction with their surroundings (above the level of spontaneous or reflexive behaviour) for more than 4 weeks.

#### Chronic VS/MCS

Chronic VS and MCS may only be diagnosed after formal assessment of PDOC in accordance with the recommendations set out in these guidelines (see [Section 2.7](#)).

VS/MCS-minus may be classified as ‘chronic’ if it has persisted for:

- > >3 months following anoxic or other metabolic brain injury, or
- > >1 year following traumatic brain injury.

MCS-plus may be classified as a ‘chronic’ if it has persisted for:

- > >9 months year following anoxic or other metabolic brain injury, or
- > >18 months following traumatic brain injury.

#### Permanent VS/MCS

Permanent VS or MCS may only be diagnosed by suitably qualified consultant physician who meets the criteria for an ‘Expert PDOC Physician’ (see [Annex 2b](#)) after the patient has been in chronic VS or MCS for at least 6 months in the absence of any measurable trajectory of change.

- > Chronic VS or MCS (plus or minus) that has been confirmed through appropriate specialist assessment may be classified as ‘permanent’ when there has been no further change in trajectory (as measured by serial application of the CRS-R) for 6 months.

It is important to note however, that any patient who remains in PDOC for more than a few months without an upward trajectory is likely to have severe permanent disability. Treatment is given in the early stages following severe brain injury in the hope of a good recovery, but must always be in the patient’s best interests and in line with their likely wishes. *Best interests* discussions should *not* be delayed until the condition is diagnosed as ‘chronic’ or ‘permanent’ but should take place whenever a treatment decision is made (see [Section 4](#)).

## Section 1 Definitions and terminology: Summary of recommendations

Recommendation	Grade <sup>a</sup>
<b>1.1 For the purpose of these guidelines the following definitions will be applied:</b>	
<p data-bbox="300 436 903 465"><b>1 Prolonged Disorders of Consciousness (PDOC)</b></p> <p data-bbox="341 506 1347 611">Patients with PDOC are those who remain in a state of wakefulness but absent or reduced awareness (ie in a vegetative or minimally conscious state) for more than 4 weeks.</p>	E1/2
<p data-bbox="300 654 600 683"><b>2 Vegetative state (VS)</b></p> <p data-bbox="341 730 1327 871">VS is defined as: <i>‘A state of wakefulness without awareness in which there is preserved capacity for spontaneous or stimulus-induced arousal, evidenced by sleep–wake cycles and a range of reflexive and spontaneous behaviours.’</i></p> <p data-bbox="341 916 1246 981">VS is characterised by complete absence of behavioural evidence for self or environmental awareness.</p>	E1/2
<p data-bbox="300 1025 743 1055"><b>3 Minimally conscious state (MCS)</b></p> <p data-bbox="341 1104 1230 1245">MCS is defined as: <i>‘A condition of severely altered consciousness in which minimal but clearly discernible behavioural evidence of self or environmental awareness is demonstrated’.</i><sup>10</sup></p> <p data-bbox="341 1290 1347 1395">MCS is characterised by <i>inconsistent, but reproducible</i>, responses above the level of spontaneous or reflexive behaviour, which indicate some degree of interaction with their surroundings.</p> <ul style="list-style-type: none"> <li data-bbox="379 1402 1225 1467">&gt; MCS-minus patients show only non-reflexive localising and pursuit movements.</li> <li data-bbox="379 1473 1334 1579">&gt; MCS-plus patients show, in addition, evidence of more complex behaviours such as language processing / communication, or interpretive non-verbal function, reasoning or problem-solving.</li> </ul>	E1/2
<p data-bbox="258 1624 676 1653"><b>1.2 Preconditions for diagnosis</b></p> <p data-bbox="341 1700 1310 1765">The following preconditions must be met before a diagnosis of VS or MCS can be made:</p> <ul style="list-style-type: none"> <li data-bbox="379 1771 1257 1800">&gt; The cause of the condition should be established as far as is possible.</li> <li data-bbox="379 1807 1070 1836">&gt; The possibility of reversible causes must be excluded.</li> <li data-bbox="379 1843 1289 1948">&gt; Assessment should be made under appropriate conditions by a trained assessor, experienced in PDOC, as described in <b>Section 2</b>. Until then the patient should be described simply as being in PDOC.</li> </ul>	E1/2
<b>1.3 Chronic, Continuing and Permanent VS and MCS</b>	

Recommendation	Grade <sup>a</sup>
<p><b>1</b> A state of VS/MCS-minus lasting for more than 4 weeks post-injury may be classified as ‘<i>continuing VS/MCS-minus</i>’.</p> <p>VS/MCS-minus may be classified as ‘<i>chronic</i>’ if, it has persisted for:</p> <ul style="list-style-type: none"> <li>&gt; &gt;3 months following anoxic or other metabolic brain injury, or</li> <li>&gt; &gt;1 year following traumatic brain injury.</li> </ul>	<p><b>RA</b> <b>E1/2</b></p>
<p><b>2</b> A state of MCS-plus lasting for more than 4 weeks post-injury may be classified as ‘<i>continuing MCS</i>’.</p> <p>MCS-plus may be classified as a ‘<i>chronic</i>’ if it has persisted for:</p> <ul style="list-style-type: none"> <li>&gt; &gt;9 months following anoxic or other metabolic brain injury, or</li> <li>&gt; &gt;18 months following traumatic brain injury.</li> </ul>	<p><b>E1/2</b></p>
<p><b>3</b> VS/MCS may be considered permanent when future recovery of consciousness becomes highly improbable. This is a clinical judgement based on a range of factors.</p> <p>The diagnosis of ‘<i>permanent VS/MCS</i>’ no longer has any legal significance, but may help to establish realistic expectations for outcome.</p> <p>As a rule of thumb, chronic VS or MCS (plus or minus) that has been confirmed through appropriate specialist assessment may be classified as ‘permanent’ when there has been no further change in trajectory for 6 months (as measured by serial application of CRS-R) (see <b>Section 2.7</b>).</p> <ul style="list-style-type: none"> <li>&gt; Permanent VS or MCS may only be diagnosed by a suitably qualified consultant physician who meets the criteria for an Expert PDOC Physician (see <b>Annex 2b</b>).</li> </ul>	<p><b>E1/2</b></p>
<p><b>4</b> Any patient who remains in PDOC for more than a few months without an upward trajectory is likely to have severe permanent disability. <i>Best interests</i> discussions regarding treatment should <u>not</u> be delayed until the condition is diagnosed as ‘chronic’ or ‘permanent’ but should take place whenever a treatment decision is made.</p>	<p><b>Legal requirement</b></p>
<p><b>1.4</b> <b>Emergence from MCS</b></p> <p>Emergence from MCS is characterised by reliable and consistent demonstration of <i>one or both</i> of the following:</p> <ul style="list-style-type: none"> <li>&gt; <b>Functional interactive communication</b> – which may occur through verbalisation, writing, yes/no signals or use of augmentative communication devices.</li> <li>&gt; <b>Functional use of objects</b> – behavioural evidence of discrimination between and intelligent use of at least two different objects.</li> </ul>	<p><b>E1/2</b></p>
<p><b>1.5</b> <b>Operational parameters for demonstrating emergence</b></p>	<p><b>E1/2</b></p>

Recommendation	Grade <sup>a</sup>
<ul style="list-style-type: none"><li>&gt; The following operational parameters should be used for demonstrating reliable and consistent responses: (see electronic Annex 1a at <a href="http://www.rcplondon.ac.uk/pdoc">www.rcplondon.ac.uk/pdoc</a>).</li><li>&gt; Functional communication – accurate yes/no responses to 6/6 basic situational orientation or autobiographical questions on two consecutive evaluations.</li><li>&gt; Functional object use – intelligent use of at least two different objects on two consecutive evaluations.</li><li>&gt; Consistent choice-making – indicating the correct choice from two pictures (at least three different pairs) on 6/6 occasions on two consecutive evaluations.</li></ul>	

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<sup>a</sup> See Appendix 1 for guide to the methodology for grading recommendations

## Section 2

# Assessment, diagnosis and monitoring

VS and MCS must be distinguished from other conditions including states of lifelong severe disability with preserved awareness, the locked-in syndrome, coma and brain death confirmed by brainstem death testing.

Table 2.1 summarises the key distinguishing features of these different conditions.

### 2.1 Diagnosis

Accurate diagnosis of VS or MCS is no longer critical for legal purposes, but is nevertheless required for clinical decision-making and treatment planning.

There is no laboratory or clinical investigation that will confirm the diagnosis of PDOC or its subcategories, VS or MCS – the diagnosis is made on the basis of careful clinical evaluation by appropriately trained professionals. It rests on clinical observation of behaviours that may suggest awareness of self and the environment.

Accurate assessment of the patient's level of awareness can be complicated by:

- > profound motor and sensory deficits, or indeed aphasia,<sup>44</sup> which may mask the behaviours that demonstrate awareness<sup>31</sup>
- > delayed and inconsistent responses, coupled with the effects of fatigue on responses<sup>45, 46</sup>
- > drawing unwarranted conclusions from assessments that are undertaken:
  - by people with little or no experience of assessing awareness
  - when a patient has other medical problems that may have affected responses
  - when a patient is affected by drugs which may reduce responsiveness
  - at an early stage when fluctuation and change may affect measurement.

Misdiagnosis remains a significant problem in PDOC,<sup>45, 47, 48</sup> and may be the result of either diagnostic error or actual change in the patient's condition over time – especially in the early stages post-injury when the level of consciousness will not infrequently improve between the points of referral and assessment.

For all of these reasons, *evaluation is required by a multidisciplinary team of clinicians* who are expert in assessing cognition, communication and motor function in the context of PDOC. Key disciplines include physiotherapy, occupational therapy, speech and language therapy, neuropsychology, nursing, and rehabilitation medicine.

## Prolonged disorders of consciousness

**Table 2.1 Differential diagnosis of prolonged disorders of consciousness**

Condition	VS	MCS	Locked-in syndrome	Coma	Death confirmed by brainstem tests
<b>Awareness</b>	Absent	Present	Present	Absent	Absent
<b>Sleep–wake cycle</b>	Present	Present	Present	Absent	Absent
<b>Response to noxious stimuli</b>	+/-	Present	Present (in eyes only)	+/-	Absent
<b>Glasgow Coma Scale</b>	E4, M1–4, V1–2	E4, M1–5, V1–4	E4, M1, V1	E1–2, M1–4, V1–2	E1, M1–3, V1
<b>Motor function</b>	No purposeful movement	Some inconsistent verbal or purposeful motor behaviour	Volitional vertical eye movements or eye blink typically preserved	No purposeful movement	None or only reflex spinal movement
<b>Respiratory function</b>	Typically preserved	Typically preserved	Typically preserved	Variable	Absent
<b>EEG activity</b>	Typically slow wave activity	Insufficient data	Typically normal	Typically slow wave activity	Typically absent
<b>Cerebral metabolism (PET)</b>	Severely reduced	Intermediate reduction	Mildly reduced	Moderately to severely reduced	Severely reduced or absent
<b>Prognosis</b> (See Section 1.7 for details)	Variable: (if permanent – continued VS or death)	Variable: (if permanent – continued MCS or death)	Depends on cause but full recovery unlikely	Recovery, VS or death usually within weeks	Organ function can be sustained only temporarily with life support

EEG = electroencephalography; MCS = minimally conscious state; PET = positron emission tomography; VS = vegetative state

However, diagnosis and management requires an interdisciplinary team-based approach, and should not depend upon isolated clinicians, whatever their profession and level of individual expertise.

The use of formal structured assessment tools can help to classify patients appropriately.<sup>48</sup> Because the emergence from coma or disordered consciousness is generally through a gradual process of recovery, serial observation to identify trends towards more consistent or higher-level responses provides the best indicator we currently have of whether or not an individual is likely to emerge from VS or MCS.<sup>40, 49</sup> Diagnosis cannot therefore be based on a single assessment, but is made through careful observation over an adequate period of time, using both detailed clinical evaluation and validated structured assessment tools.

### Involvement of friends and family

Families and close friends play a key role in the assessment and diagnosis of patients with DOC because they are often present over prolonged periods and because many patients respond at an earlier stage with familiar people. Family members may often see responses that the team do not but, on the other hand, they may sometimes interpret simple reflexive movements as more purposive interactions. They need to be fully consulted and involved in the assessment process and provided with information and support from clinicians who can explain what behaviours to look for (see electronic Annex 2e at [www.rcplondon.ac.uk/pdoc](http://www.rcplondon.ac.uk/pdoc)).

There are several ways to involve family members in the formal assessment process (if they so wish):

- > They may be actively involved during formal and informal assessments by the team to observe the patient's responses to a familiar face or voice.
- > It is often also helpful to ask them to use videos to record their interactions outside of formal sessions.
- > Tools such as the Wessex Head Injury Matrix (WHIM) or Coma Recovery Scale-Revised (CSR-R) can be used as a structured framework for interview to record their observations, so that these can be reviewed and interpreted by the clinical team.
- > The SMART-INFORMS presents a structured framework interviewing and documenting the observations of families and friends, and informs the SMART assessor where it is necessary to investigate their observation jointly with the family/team in context.

(See 'Principles of clinical assessment' for more information on these tools).

## 2.2 Principles of clinical assessment

A person's level of awareness is judged on the basis of their behaviour, which requires that they can receive at least some sort of sensory input and has control over at least some motor output. Misdiagnosis most commonly arises from failure to recognise that the patient is deaf, blind, aphasic or that responses are masked by paralysis, physical status or position.<sup>47</sup>

The diagnostic assessment process should follow a structured approach and should consider:

### 1 Causation

- > Before formal assessment, the cause and extent of the brain damage must be established;

- there should be evidence of widespread damage to both cerebral hemispheres and the basal ganglia bilaterally (caution is essential if damage in those areas is limited, but there is significant brainstem and mid-brain damage).
- > Any treatable causes/ contributing factors to PDOC should also be ruled out;
  - especially sedating medication.

### 2 Primary neurological pathways

- > Evidence that the primary motor, sensory, visual and auditory pathways are sufficiently intact to allow evidence of awareness to be detected.
- > Evidence of specific localised damage may suggest specific impairments that might complicate the assessment to be accounted for during evaluation.<sup>44</sup> For example:
  - marked damage to the dominant hemisphere in contrast to the non-dominant hemisphere would raise the possibility of aphasia
  - evidence of localised damage to the posterior circulation or brainstem may raise the possibility of a locked-in syndrome, rather than disordered consciousness.

### 3 Behavioural evidence of awareness/responsiveness

- > Indicating the extent to which the patient has self or environmental awareness. The framework for a standard clinical evaluation is given in the next section.

A comprehensive scheme for clinical evaluation based on the principles above is given in electronic Annex 2a at [www.rcplondon.ac.uk/pdoc](http://www.rcplondon.ac.uk/pdoc).

## Standard clinical evaluation

A standard clinical evaluation should include the following:

### Detailed clinical history, examination and general investigation

- > To identify the cause of brain injury and any complications arising from it
  - this requires the doctor to review the medical records and reports on imaging related to the first 4 weeks of the disorder.
- > To exclude other conditions (eg metabolic/infectious disorders, hydrocephalus, 'syndrome of the trephined') that may impair consciousness.†

### Review of medication

- > To identify and, if possible, withdraw or reduce any drugs which could affect arousal.
  - common unnecessary drugs may include anticonvulsants, antispasticity drugs, opiate analgesic drugs and sedatives.

**Detailed neurological evaluation** by an experienced clinician to include assessment of:

- > primary visual pathways:
  - pupillary light reflex, response to visual threat or bright light, or evidence of visual tracking.
- > primary auditory pathways:
  - startle or blink reflexes in response to sudden loud noises, or any evidence of localisation towards sound.
- > primary somatosensory pathways:

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† Syndrome of the trephined ('sinking skin flap syndrome') is a condition where neurological deterioration occurs following removal of a skull bone flap. It often manifests as patients becoming more sleepy as the skull defect sinks in when the patient is sat up. It may be partially or fully reversed by cranioplasty.

- stretch reflexes, response (eg facial grimace) to touch or pain.
- > primary motor output pathways
  - any spontaneous or reflex or automatic movements of the face, mouth or limbs.
- > spinal pathways
  - does a painful stimulus applied to the limbs cause facial movement and vice versa?

### Investigations

After the clinical evaluation one should consider investigations. No standard or routine investigations are needed for patients in PDOC. The general principle that investigations are only appropriate if: a) the result will alter clinical management; and b) it is considered to be in the patient's best interests – these must always be taken into account.

**Standard imaging** (computed tomography (CT) or magnetic resonance imaging (MRI) scan of the brain)

Brain imaging will have been undertaken in the acute phase of care, and should be reviewed to ensure that the nature, extent and location of brain damage is known.

Once a patient is in a prolonged DOC (ie >4 weeks after onset), repeat imaging is not routinely required. However, brain imaging may still be necessary in certain circumstances which include the following:

- > to exclude undiagnosed or new specific structural, operable causes of the state
- > if the doctor considers it is justified to determine the extent and location of brain damage for clinical decision-making or to aid in giving a prognosis.

Deciding the best modality for imaging demands collaborative discussion between the responsible physicians, neurosurgeons, and neuro-radiologists. A CT scan is usually sufficient for the exclusion of hydrocephalus and other remediable causes, while MRI scans may provide better visualisation of localised damage or late atrophy.

### Hydrocephalus

Enlargement of the ventricles is an almost inevitable feature of cerebral atrophy secondary to chronic diffuse brain injury. However, post-traumatic hydrocephalus may develop many months after injury and a small but significant group of patients may benefit from a CSF diversion procedure such as a ventriculoperitoneal shunt.

- > If there is clinical reason to suspect hydrocephalus (for example markedly fluctuating or deteriorating consciousness in patients with previous trauma, infection or sub-arachnoid haemorrhage) this may warrant further specific investigation through an extended lumbar drain test, CSF infusion studies<sup>50</sup> or intracranial pressure monitoring.
- > However, the interpretation of the findings is not straightforward in the context of PDOC. Units specialising in the management of PDOC should establish cooperation with a neurosurgical service that has the appropriate expertise and resources for managing this potentially high-risk group of patients.
- > It is not appropriate to undertake invasive procedures such as high-volume CSF removal via a lumbar puncture in a rehabilitation setting.

Similar considerations apply to patients who might develop a syndrome of the trephined after decompressive craniotomy.

### Other investigations

Other investigations are rarely needed, but might include

- > **EEG**, which is only helpful in the rare circumstance that ongoing subclinical epileptic seizure activity seems a plausible cause for altered consciousness.
- > **Sensory evoked potentials** (visual or auditory) may help to establish whether primary sensory pathways are / are not intact if clinical testing reveals a lack of visual or auditory startle response. (This information may help to target clinical evaluation appropriately).
- > **Nerve conduction studies**, including transcranial motor stimulation, which would only be needed if very severe neuropathy were considered likely.

**Apart from the above, electrophysiological tests and more sophisticated imaging techniques (such as fMRI, PET scans etc) do not form part of routine clinical evaluation for patients with PDOC – see Section 2.4 for more detail.**

### Clinical assessment of behavioural responses

Clinical assessment of the level of responsiveness and awareness depends on observation of behavioural responses. It is important to distinguish between:

- > the actual behaviour observed and
- > the interpretations made from or attributions placed on the behaviour.

Three types of behavioural observations may contribute:

- > spontaneous behaviours, not requiring external stimuli
- > behaviours occurring in response to normal incidental stimuli
- > behaviours occurring when using structured, planned stimuli.

Information may come from several complementary sources including:

- > review of the clinical notes for routine observations recorded by staff during daily care and/or activities
- > observations made by relatives and friends, usually gathered from interview, and/or systematically recorded by them, including videos
- > observations made by staff during routine clinical care, recorded contemporaneously
- > observations made specifically by trained staff using both informal clinical evaluation and formal structured assessment protocols designed to investigate level of response.

### Formal structured observational assessment of behavioural responses

The mainstay of assessment is through detailed clinical evaluation by skilled professionals with specific experience of PDOC. Structured assessment using validated tools to quantify the level of response provides a sound basis for recording change over time. Formal assessment using a structured behavioural assessment tool should be part of an overall assessment, but should not be the only assessment undertaken.

The term '*SMART assessment*' is sometimes used as a generic short-hand term for formal structured assessment of PDOC (rather as the trade name '*Hoover*' is commonly used instead of 'vacuum cleaner'). This has caused confusion – for example the courts have sometimes ordered 'a SMART assessment' in the erroneous belief that application of the SMART tool itself (see below) is an essential requirement of these guidelines.

For clarity the GDG would like to emphasise that, although useful in some circumstances, the SMART tool is just one of the structured tools available and is not an essential part of evaluation. For the most part a sound assessment may be achieved though detailed clinical evaluation with the addition of the CRS-R and/or WHIM.

Further advice on the use of structured assessment tools is given below.

In order to encourage some degree of consistency for recording longitudinal outcomes, it is appropriate to agree a limited set of recommended instruments. Some of the tools can be time-intensive to administer, however, so a balance must be found between the need for standardised information for research and to inform clinical decision-making and what is pragmatic to deliver. Ultimately, the choice of tools should be determined by the goal – to measure the level of awareness, particularly during the period of change, or to look for areas that may need more detailed evaluation and intervention, but the CRS-R should be used as the minimum requirement.

The WHIM and the CRS-R are suitable for monitoring over an extended period of time, whereas the SMART provides an in-depth assessment, with opportunities for 'deep-dive' investigative exploration into specific behaviours in the case of uncertainty. The SMART is also designed inform a bespoke intervention and/or management programme targeted around the individual's particular profile of responses, where clinically relevant.

Formal assessment is essential in the following circumstances:

- > to establish initial diagnosis and behaviours as a baseline to guide future management
- > as part of a formal review of their clinical state when the patient has reached the end of the expected recovery period (see definitions of permanent VS and MCS in [Section 1](#))
- > as part of the assessment when making decisions about the potential withdrawal of active medical treatment (specifically CANH)
- > if there is significant disagreement between different parties on the clinical state (for example if family members and clinical staff disagree).

It should also form part of monitoring during formal reviews in long-term care.

Assessment should be undertaken by a clinical team with specific training, skills and experience in the evaluation of patients with PDOC. Formal standardised evaluation should be performed under appropriate conditions with particular attention given to those listed in Table 2.2.

Minimum requirements for assessor training/experience are given in electronic Annex 2b at [www.rcplondon.ac.uk/pdoc](http://www.rcplondon.ac.uk/pdoc). More detail on optimising conditions for assessment is given in electronic Annex 2c at [www.rcplondon.ac.uk/pdoc](http://www.rcplondon.ac.uk/pdoc).

## 2.3 Diagnostic tools

The Glasgow Coma Scale (GCS) is widely used in acute settings to evaluate the level of consciousness. The GCS may be used as a screening tool to identify patients with PDOC, but patients in VS and MCS may exhibit any of the features highlighted in purple in the following table, and so may have scores in the range of 3–12/15. It is therefore not a valid diagnostic tool for VS and MCS. It should also be noted that patients with locked in syndrome may score lower than patients in PDOC.

### The Glasgow Coma Scale

Eye opening	Motor function	Verbal response
1. None	1. None	1. None
2. To pain	2. Extends to pain	2. Grunts/moans
3. To sound	3. Abnormal flexion to pain	3. Inappropriate words
4. Spontaneously	4. Normal flexion / withdrawal to pain	4. Confused
	5. Localises pain	5. Orientated
	6. Normal – follows commands	

### Structured assessment tools

A review by the US Task Force<sup>51</sup> identified 13 instruments, of which six could be used to assess DOC with minor/moderate reservations. Three of them are commonly used in the UK:

- > the JFK Coma Recovery Scale – Revised (CRS-R)<sup>51, 52</sup>
- > the Wessex Head Injury Matrix (WHIM)<sup>46, 53</sup>
- > the Sensory Modality Assessment and Rehabilitation Technique (SMART).<sup>54, 55</sup>

The CRS-R had the strongest evidence for validity and is the most widely used tool across the world. It is freely available, simple to apply and suitable for serial measurement. It has now been validated in several languages and there is an international drive to adopt the CRS-R as part of their standardised assessment battery in order to support international comparison both for assessment of clinical outcomes and for research.

However, validity is not the only criterion for choosing an instrument. A UK survey conducted in 2012<sup>56</sup> showed that the WHIM and the SMART were also widely used. Many centres specialising in this area use more than one of these tools, as they provide complementary information.<sup>57</sup>

In order to support consistency and international comparison the GDG recommends the use of *one or more* of these three instruments for formal structured assessment of PDOC. *If only one is used it should be the CRS-R.*

Table 2.2 Conditions for assessment of the level of consciousness

<b>Health</b>	<ul style="list-style-type: none"> <li>&gt; The patient's clinical state should be documented, and assessment postponed if there is a short-term, reversible intercurrent infection or other problem.</li> <li>&gt; However, some patients have recurrent or persistent additional problems, and then assessment should be undertaken but interpreted cautiously. Continued medical complications in themselves are markers of a poorer outcome.</li> </ul>
<b>Posture and positioning</b>	<ul style="list-style-type: none"> <li>&gt; The patient's posture (relationship of one part of the body to another) must be optimised for comfort, with or without orthoses, and reasons for this posturing (pain, hypersensitivity, spasticity) looked for and treated.</li> <li>&gt; Their position (relationship of the body to the environment) for assessment purposes should be varied when assessing arousal and awareness. <ul style="list-style-type: none"> <li>– Ideally, they should be assessed in an upright a position and as close to midline as possible. When this is difficult or contraindicated then the assessment should be carried out in the best position achievable, but any impact of positioning should be recorded.</li> </ul> </li> </ul>
<b>Environment</b>	<ul style="list-style-type: none"> <li>&gt; The immediate micro-environment should be adequately lit, and free from avoidable noise and distraction. (However, incidental and unpredictable stimuli may sometimes help in the assessment.)</li> <li>&gt; Different macro-environments should also be explored as opportunity allows – eg gardens, places of worship, around pets etc.</li> </ul>
<b>Avoiding overstimulation /fatigue</b>	<ul style="list-style-type: none"> <li>&gt; If fatigue is evident, the assessment may need to be divided into short periods, with rest periods both prior to and after assessment and during any breaks.</li> <li>&gt; Fatigue, however, should be differentiated from other causes of low arousal.</li> </ul>
<b>Arousal</b>	<ul style="list-style-type: none"> <li>&gt; If difficult to arouse, remediable causes should be considered. These may include infections, medication, poor sleep hygiene, hydrocephalus, non-convulsive status epilepticus, or pseudo states such as inability to open their eyes due to bilateral third nerve palsy.</li> <li>&gt; Patients should be assessed when they are most likely to be alert.</li> <li>&gt; If sedative medication is given and is essential, then the assessment should be undertaken shortly before the next dose, if possible.</li> <li>&gt; Managing competing impairments (eg spasticity and arousal) is often challenging, however, and may need to be prioritised in accordance with individual needs.</li> </ul>
<b>Type of stimulation</b>	<ul style="list-style-type: none"> <li>&gt; It is essential to assess baseline spontaneous or reflexive behaviours at rest before applying different stimuli.</li> <li>&gt; Clinicians should use stimuli that the patient is familiar with, if known and available – these may include music and other stimuli that they either liked or disliked prior to their injury.</li> <li>&gt; It may be helpful to have a close friend or family member present during an assessment, to provide a familiar voice and sight.</li> </ul>

However, the list is not intended to be exclusive. Clinicians may continue to use other instruments in addition to these if they find them clinically useful in specific circumstances. Other available tools include the Sensory Tool to Assessment Responsiveness (STAR)<sup>58</sup> and the Music therapy Assessment Tool for Awareness in Disorders of Consciousness (MATADOC).<sup>59, 60</sup>

(The latter can only be applied by a music therapist, but may be used to assess auditory awareness and might have particular value for patients who are thought to be blind).

### JFK Coma Recovery Scale – Revised

The CRS-R has 25 hierarchically arranged items with six subscales (auditory, visual, motor, oromotor, communication and arousal).

- > Scoring is based on the presence or absence of specific behavioural responses to stimuli presented in a standardised manner, from reflexive responses to cognitively facilitated responses.
- > The revised scale was developed to differentiate between the diagnosis of VS and that of MCS and is shown to be valid and reliable in this context.<sup>51, 52</sup>

Further information and free download of the CRS-R are available from the Centre for Outcome Measurement in Brain injury (COMBI) website: [www.tbims.org/combi/crs/](http://www.tbims.org/combi/crs/)

### The Wessex Head Injury Matrix

The WHIM is a 62-item hierarchical scale, which provides a sequential framework of tightly defined categories of observation covering an individual's level of responsiveness and interaction with their environment. Behaviours may occur either spontaneously or in response to stimulation.

Designed to be applied by different members of the multidisciplinary team, it was developed to monitor changes from coma through to emergence from post-traumatic amnesia in patients with traumatic brain injury. It is shown to be valid and reliable in that context,<sup>46, 53</sup> but it also has applicability in other causes of PDOC.

Further information and purchase details are available through Pearson Clinical Assessment: [www.pearsonclinical.co.uk/Psychology/AdultCognitionNeuropsychologyandLanguage/AdultGeneralAbilities/WessexHeadInjuryMatrix\(WHIM\)/WessexHeadInjuryMatrix\(WHIM\).aspx](http://www.pearsonclinical.co.uk/Psychology/AdultCognitionNeuropsychologyandLanguage/AdultGeneralAbilities/WessexHeadInjuryMatrix(WHIM)/WessexHeadInjuryMatrix(WHIM).aspx)

### The Sensory Modality Assessment and Rehabilitation Technique

The **SMART** is designed to examine both the motor and communication responses across the five sensory modalities (visual, auditory, tactile, olfactory and gustatory).

- > Responses in each modality are assessed on a five-point hierarchical scale for both motor and functional communication.
- > Findings are summarised in terms of the SMART level and frequency of behaviours across each modality to provide a SMART profile.
- > The highest overall responses provide the indicative diagnosis of VS, MCS- and MCS+, and highlights any indications of emergence.

It has recently been updated to the **SMART – Profile Version 3**. Validity is maintained through the unchanged standardised core and advanced techniques, but the assessment now enables further targeted exploration of positive responses through specific non-standardised techniques following the assessor's clinical reasoning.

Assessments can only be administered by a trained and accredited SMART assessor, to meet the RCP requirements, and are administered over only one set of 10 sessions within a 2–3-week period, with bespoke follow-up intervention and management plans.

Further information about the SMART – Profile Version 3 may be found on the website: [www.rhn.org.uk/what-makes-us-special/services/smart/](http://www.rhn.org.uk/what-makes-us-special/services/smart/)

### Pros and cons of the various tools

There are pros and cons to the use of any of these tools, which may govern their selection by clinicians for routine use. In addition to the utility and cost considerations listed in Table 2.3, there are a number of practical considerations.

#### CRS-R

- > The CRS-R is a simple and easily repeatable tool.
- > Although it lacks the range of sensory modalities accorded by the SMART, it covers a broadly similar range of responses.
- > It is increasingly accepted as the common international measurement tool for describing the level of consciousness and for monitoring change over time.
- > It allows simple measurement of the level of awareness on a regular basis (eg weekly), which is invaluable when a patient is changing.
- > There is no ceiling on the number of times it can be applied, making it a suitable tool for longer-term monitoring.

#### WHIM

- > The WHIM items cover a different range of responses from the SMART and CRS-R. Its ceiling extends beyond that of the CRS-R or SMART to track patients until they emerge from post-traumatic amnesia.
- > It records both spontaneous (but meaningful) behaviours and those elicited by stimulation.
- > Because it can be easily applied in the course of clinical practice by different members of the multidisciplinary team, the WHIM offers a simple practical tool for use in more generalist settings.
- > Although not formally validated for this purpose, experience demonstrates that family members can also be trained quite easily to use the WHIM to record the responses that they observe.
- > A serial record of WHIM scores can be used to monitor the consistency of responses, as well as trends towards change over time.<sup>18, 53</sup>
- > The WHIM has been criticised by some clinicians for its over-reliance on visual stimuli, and some items are noted to be out of order in the hierarchy.<sup>18</sup> An updated version is currently in development but not yet published.
- > Like the CRS-R, it also allows simple measurement of the level of awareness on a serial basis to capture changing levels of responsiveness over time. With no ceiling on repetition it is also suitable for longer-term monitoring.

#### SMART

- > The SMART is a detailed assessment and investigative tool originally designed to identify areas for intervention, and can also be used to distinguish patients in VS from patients in MCS- and MCS+ for both motor and functional communication for all modalities through evaluating behavioural responses.

- > The additional use of the auditory feedback switch, and the extended range of sensory modalities (smell and taste), can be useful when evaluating patients who may have marked sensory and motor impairments.
- > Family and team perspectives are recorded and explored collaboratively through the SMART-INFORMS.
- > The prolonged assessment (in 10 applications over 2–3 weeks) ensures that the assessor is very familiar with the patient’s repertoire.
- > Stringent training and accreditation programmes (currently a 2–5-day training course but with distance learning packages planned with support from mentor on first SMART report) ensure that the SMART is consistently applied by trained assessors. This limits the availability where clinical teams do not have resources to commit to extended training.

*None of the above tools are interval level measures. All are designed to be interpreted at item level by staff with suitable experience and training (for example an Expert PDOC Physician or an Expert PDOC Assessor with the relevant training – see Annex 2b).*

### Recording over time

Inconsistency of response is a hallmark of MCS, therefore any structured assessment must be applied over time for complete assessment. The number of assessments and the time over which assessment is made will depend upon many factors including the purpose of assessment, the degree of variability, uncertainty etc.

A fundamental difference in approach between the CRS-R or WHIM and the SMART is that the former two tools are normally applied serially over the period of assessment, however long or short. By contrast SMART is normally delivered in a short but intensive period comprising 10 assessments over 2–3 weeks.

Clinical teams should be aware of the burden of repeated assessment, both for the patient and in terms of staff time. Multiple serial assessments may well be justified in the context of continuing clinical uncertainty, but should not be done simply as a matter of routine.

Causes of clinical uncertainty may include:

- > a fluctuating or changing medical condition
- > variable responses or arousal
- > different perceptions between the family and the treating team, or
- > a suspected trajectory towards change.

Any programme of assessment should be conducted under the supervision of an appropriately experienced PDOC assessor who is responsible for reviewing the findings to determine whether further standardised assessments are justified or required.

Table 2.3 Utility and cost considerations for the three structured assessment tools

<b>Reliability and validity</b>	All of these three tools have acceptable published evidence of reliability and validity, and have been identified by Seel <i>et al</i> <sup>51</sup> as being appropriate for clinical practice.
<b>Administration time</b>	<ul style="list-style-type: none"> <li>&gt; The WHIM and the CRS-R each take about 20 minutes to document systematically with formal testing of behaviours (so a total of about 3 hours to administer on 10 occasions).</li> <li>&gt; The SMART is a diagnostic and clinical tool. It takes 5–6 hours of trained therapy time to administer and document over the full 10-session course, but also provides an additional level of detail.</li> </ul>
<b>Frequency and duration</b>	<ul style="list-style-type: none"> <li>&gt; CRS-R and WHIM assessments are conducted serially over the period of assessment to evaluate any trajectory towards improvement. Ideally they are administered at different times of day and in a variety of positions – usually at a rate of 2–3 per week. (The period of evaluation may vary according to clinical need. For a snapshot evaluation, the CRS-R originators recommend a minimum of six assessments over a 2-week period, but both tools can be applied serially for longer-term monitoring as appropriate with no ceiling on the number of applications).</li> <li>&gt; The SMART is administered as an intensive but thorough assessment of 10 sessions (five morning and five afternoon) over a 2–3-week period.</li> </ul>
<b>Training and/or accreditation</b>	<ul style="list-style-type: none"> <li>&gt; Training is not mandatory for the CRS-R or WHIM, but training is shown to improve reliability<sup>46, 52</sup> and studies to date have been largely conducted with trained assessors. Formal training programmes are currently available from a number of centres in the UK. A training DVD for the CRS-R is also available from the originators.</li> <li>&gt; Training and accreditation is mandatory for the SMART. All practitioners need to have accessed either distance learning pages and/or on-site training tailored to the delegates specific requirements. The course is held at the Royal Hospital for Neurodisability, Putney, or at local units as required.</li> </ul>
<b>Costs and copyright</b>  (Current at time of going to press. These may change over time)	<ul style="list-style-type: none"> <li>&gt; The CRS-R is not restricted by license and is free to download and use. There is no requirement for professional qualification.</li> <li>&gt; The WHIM is copyright-restricted. The manual and copies of the tool can be obtained from Pearson (<a href="http://www.psychorp.co.uk">www.psychorp.co.uk</a>) at a cost of £59 for the manual and £2.23 per individual record sheet (providing 15 assessments). There is a requirement for professional qualification</li> <li>&gt; The current cost of the SMART course ranges from free places to £750 for the full 5-day course or price on application for combined online training and short course. Costs are inclusive of full mentorship for the completion of the first SMART report, ongoing support for accredited assessors and free download of the SMART-PROFILE manual, techniques guidebook, SMART forms and SMART cards. Professional qualification is required. For further information on training email: <a href="mailto:smart@rhn.org.uk">smart@rhn.org.uk</a>.</li> </ul>

A more detailed comparison is given in electronic Annex 2d at [www.rcplondon.ac.uk/pdoc](http://www.rcplondon.ac.uk/pdoc). CSR-R = JFK Coma Recovery Scale – Revised; SMART = the Sensory Modality Assessment and Rehabilitation Technique; WHIM = the Wessex Head Injury Matrix

## 2.4 Imaging and electrophysiology

The role of functional imaging (such as functional magnetic resonance imaging (fMRI) and positron-emission tomography (PET) scans) and electrophysiology has been under investigation for some two decades.<sup>61–63</sup> The potential advantage of these approaches is that they can be used to demonstrate distinct and specific physiological responses (eg changes in regional blood flow) in response to specific external stimuli, in the absence of any discernible behavioural response.

### Brain imaging

Imaging may be structural or functional.

- > Structural imaging offers a vision of the structure of the brain to enable diagnosis of larger-scale diseases, tumours, injuries and stroke. Recent techniques, such as diffusion tensor imaging allow more detailed visualisation of the neural tracts.
- > Functional imaging offers the opportunity to visualise the relationship between activity in certain brain areas and specific sensory stimuli or mental functions.

fMRI has been used in association with cortical activation techniques to assess patients' ability to generate wilful responses (detected by neuroanatomically specific changes in blood-oxygenation level) during different mental imagery tasks.<sup>64</sup> Resting-state fMRI (without any stimulus) can also be used to assess connectivity within areas of the brain, which is reported to be decreased in severely brain-damaged patients, in proportion to their degree of consciousness impairment.<sup>65</sup>

However, there are a number of challenges to the use of these techniques:

- > Functional brain imaging paradigms are costly to implement and infrastructure to support them is not present in most clinical MRI centres.
- > The clinical significance of the imagery findings has not yet been established and particular caution is required when interpreting negative results. About one in five normal volunteers are unable to generate fMRI activity on motor imagery tasks, so negative results in an MCS patient do not necessarily indicate lack of awareness.
- > They are also time-consuming to apply and many patients are not suitable for these techniques, including those who:
  - have implanted non-MRI compatible metal work (which may include some programmable shunts)
  - are unable to tolerate lying supine for at least an hour
  - require regular suctioning (eg of a tracheostomy)
  - have involuntary movements such as spasm, teeth grinding or regular head rotation / extension, which have obvious detrimental effects on the quality of data.<sup>66</sup>
- > While it is acknowledged that there is a small cohort of patients who present behaviourally as being in VS but demonstrate covert responses within an fMRI scanner, the prognostic significance of these findings is as yet unclear. This raises the ethical dilemma of whether or not and how to disclose this information to clinicians and patients' families.<sup>67</sup>

More recently, passive examinations that do not require the patient to respond have been used to explore the underlying structural integrity of the defined cortical networks that are thought to be related to consciousness.

- > Diffusion tensor imaging (DTI) can be used to examine the structural integrity of the brain.<sup>68</sup> For example, in one small study, the structural integrity of white matter in the subcortical and thalamic regions distinguished VS and MCS with 95% accuracy.<sup>69</sup>
- > PET of <sup>18</sup>F-fluorodeoxyglucose (FDG) has been used to investigate metabolic activity (glucose consumption) of the brain, examining activity – both overall and in specific parts of the brain. A recent multicentre study found that the minimal activity necessary to produce a conscious state was 42% of normal. In addition, PET scan activity specifically predicted the outcome (recovery to consciousness) in 88% of subjects.<sup>70</sup>

These techniques may have potentially greater clinical application than activation studies, because imaging may in future be undertaken in non-research/non-specialist centres. However, they are not currently widely available in the UK.

### Electrophysiology

Electrophysiological approaches have been under exploration in the PDOC literature for longer than dynamic imaging, much of the literature dating back to the 1970s.

Although patients with VS and MCS show a variety of abnormalities on EEG, the main application of the resting EEG has been in the acute environment, for example to exclude subclinical seizure activity, metabolic encephalopathy etc as a prerequisite for assessment.

Sensory evoked potentials (SEPs), such as visual, brainstem auditory and somatosensory evoked potentials, are recognised as useful objective measures of the integrity of basic sensory pathways. As noted in [Section 2.2 – Investigations](#), they may be useful to confirm or refute pathway disruption and so help to avoid misdiagnosis due to visual or auditory impairment.

Cognitive evoked potentials (CEPs) can potentially offer bedside measures of basic higher order function, such as aspects of language processing. A number of paradigms have been explored, of which the P300 (a wave among event-related potentials) is thought to reflect higher-level processing. Numerous studies have examined its use to distinguish different levels of disordered consciousness,<sup>71</sup> but a recent meta-analysis showed poor predictive value of paradigms such as P300 in comparison to standard EEG and basic oscillatory reactivity in response to eye opening and other stimuli.<sup>72</sup>

### In summary

It is important to distinguish basic clinical evaluation using CT/MRI imaging and standard EEG (with or without visual or auditory stimulation) as described in [Section 2.2](#) from the more sophisticated techniques described in this section.

The overwhelming consensus of clinical commentary and peer review is that more advanced brain imaging and electrophysiology techniques have provided valuable insights into this patient group, and will continue to provide an important focus for research. However, the evidence base has not yet reached a stage of development where these could be considered to be part of routine clinical practice.

More work is required to improve our understanding of how these investigations should be interpreted, and whether or how they could contribute to decision-making. At the present time it remains unclear whether they are capable of informing the diagnosis beyond detailed clinical and behavioural assessment over time, and whether they have any prognostic utility in the early stages post-brain-injury.

**Currently, therefore, these more hi-tech investigations do not form part of the standard assessment battery, nor do they represent a ‘practicable step’ required by s.1(3) MCA to support a person’s capacity to make relevant decisions. They should be only applied in the context of a registered research programme.**

Wherever they are used in research, imaging and other techniques *must* be accompanied by optimised clinical evaluation so that data on the clinical validity of these tests can be accumulated. This requires expert multidisciplinary assessment by appropriately experienced staff in specialist centres, conducted systematically using validated structured tools and repeated over adequate periods of time, (as described in subsection 2.2, [Principles of clinical assessment](#)).

## 2.5 Interventional programmes

### Medication

A number of recent systematic reviews have explored the evidence for effectiveness of interventions for PDOC including a variety of medications, neurostimulation and sensory stimulation programmes.<sup>73–76</sup> The evidence base from the literature may be summarised as follows:

- 1 The primary intervention to be considered in all cases and at all times is the reduction and/or withdrawal of any drugs that may reduce responsiveness or awareness.
- 2 Stimulatory medications that have been explored include:
  - > dopaminergic drugs (levodopa, amantadine and bromocriptine)
  - > gaba-ergic drugs (eg zolpidem)
  - > medications that inhibit the reuptake of serotonin and/or noradrenaline in the presynaptic nerve terminal (eg methylphenidate, serotonin reuptake inhibitors).
- 3 Much of the research is limited, being based on single-case / open-label studies. Overall the evidence for their effectiveness is weak or conflicting:
  - > Initial enthusiastic reports of extraordinary zolpidem-induced arousal from a semi-comatose state<sup>77, 78</sup> have not been replicated. The only formal randomised controlled trial (RCT) of zolpidem in this context<sup>79, 80</sup> suggested that approximately 5% of patients (mainly in MCS at baseline) showed a transitory response lasting 1–2 hours, but daily no evidence of lasting benefit or cumulative effect. The response was sometimes followed by drowsiness and tended to wear off over time.
  - > Methylphenidate may improve attention and speed of mental processing in higher-level brain-injured patients,<sup>81</sup> but does not appear to improve responsiveness in patients with PDOC.<sup>82</sup>
  - > The only level 1 evidence for benefit of medical intervention is for the use of amantadine. In a double-blind placebo-controlled trial of amantadine (100–200 mg bd) given for 4 weeks in patients presenting between 4–16 weeks post-injury, the treatment group showed a faster recovery on the Disability Rating Scale.<sup>83</sup> However, its longer-term effects and the benefits outside of this early intervention window require further exploration.

- 4 At the current time, there is insufficient evidence to make formal recommendations regarding the use of medication to enhance arousal/awareness.

The question of whether or not to try medication, and choice of agent, is a matter for clinicians to decide. Any decision to prescribe medication should be on the basis of *best interests*, weighing up the balance of benefits and harms, which should be clearly discussed with the family.<sup>42, 43</sup> If a decision is made to proceed, this should only be on the basis of an individual therapeutic trial (A-B-A design) using a single agent at a time, with formal monitoring (eg with the CRS-R administered daily) to observe the impact of the medication (preferably by observers unaware when active treatment is started and finished).

### Neurostimulation

A variety of techniques applying direct electrical or magnetic stimulation of the brain have been explored, including deep brain stimulation,<sup>84</sup> dorsal column stimulation,<sup>84</sup> and trans-cranial magnetic stimulation.<sup>85</sup>

The cumulative evidence from 202 patients in an uncontrolled case series suggested that approximately 20% of patients may make small gains in motor or verbal function.<sup>73</sup> However, the gains are modest for the most part and there are significant ethical concerns about the use of invasive techniques such as electrode implantation in patients who are unable to give consent to treatment, when the balance of benefits and harms is unknown.<sup>86</sup> The recent AAN literature did not find strong enough evidence to include any of these techniques as part of routine clinical practice.<sup>28, 29</sup> Such techniques should therefore only be used as part of an ethically approved and registered research programme.

### Sensory stimulation, including oral trials

The human brain grows and adapts through use and is responsive to external stimulation.<sup>87</sup> Consequently, many authors have employed sensory stimulation programmes to try to enhance responsiveness.<sup>88</sup>

A Cochrane systematic review in 2004<sup>76</sup> found only three relatively low-quality controlled studies of coma arousal programmes and concluded that there was no reliable evidence to support or rule out the effectiveness of multisensory programmes for patients in coma or vegetative state. However, a more recent review by Padilla *et al* in 2016<sup>89</sup> has provided stronger evidence that short term multimodal sensory stimulation (1–2 weeks) can help to improve arousal and clinical outcomes for people in coma or VS following traumatic brain injury – especially if stimuli are associated with the person’s past experiences and preferences.

A number of studies have explored specific interventions including oral trials (tastes of food) and music therapy<sup>90</sup> or other familiar/contextual stimuli.<sup>91</sup> In particular, oral trials can sometimes elicit behaviours such as anticipatory mouth opening or watching the spoon approach. They may also provide a useful functional context in which to observe for evidence of interaction. However, they should only be initiated by a speech and language therapist (SLT) who is able to determine if the swallow is safe enough. (Further guidance is available from *Guidelines for Speech and Language Therapists working with adults in a Disorder of Consciousness (DOC)* [www.rhn.org.uk/content/uploads/2019/09/SLT-PDOC-guidelines-2019.pdf](http://www.rhn.org.uk/content/uploads/2019/09/SLT-PDOC-guidelines-2019.pdf)).

The overall strength of evidence for these interventions is limited by small sample sizes and short intervention periods with no long-term follow-up. Nevertheless, the findings resonate with

clinical experience that controlled stimulation provides the best opportunity to observe responses. In addition, some families and friends may welcome the opportunity to have a positive role to offer during visiting times.

Many patients with PDOC demonstrate a degree of hypersensitivity, so care should be taken to avoid over-stimulation, or bombardment with multiple stimuli at the same time, as these can trigger sympathetic over-activity. In general, stimulation should focus on pleasant sensations (such as favourite music, familiar pets, gentle massage etc) offered one at a time for short periods to minimise sensory overload.

## 2.6 Other structured assessments – symptom monitoring

A particular concern for families and those caring for patients with PDOC is that they may be experiencing unpleasant symptoms such as pain and depression. Even though patients in VS are considered to be unaware, and therefore unable to experience the emotional consequences of pain, they may display physiological signs suggestive of pain. For example, several authors have demonstrated that, although there is some relationship between pain scores and level of consciousness assessed using the CRS-R, the relationship is not entirely robust.<sup>92, 93</sup> Pain is a primitive response and it appears that at least some patients who are behaviourally in VS at least respond to pain and so may be able to perceive it. This overriding concern often results in clinicians prescribing pain relief, if only to reassure families and themselves.

The evidence available suggests that patients in MCS have unimpaired ability to experience pain (and presumably other symptoms).<sup>94</sup> By definition, however, they are unable to report their pain symptoms reliably using standard methods such as visual analogue scales, so assessment must rely on the observation of pain-related behaviours.

For all of the above reasons, clinicians are urged pay careful attention to the prevention, management and monitoring of pain/discomfort for patients with PDOC (see [Section 4](#)).

### Pain

Schnakers *et al* have developed the Nociceptive Coma Scale (NCS-R)<sup>95</sup> as a tool to assess awareness or response to nociception (fingernail pressure) in patients with PDOC. Formisano (2018) has demonstrated that the NCS-R applied to a person-specific pain stimulus (eg passive movement of the arm or the head, or anything else that the team has observed leads to grimacing or other signs of a pain response) may be more sensitive than the NCS-R applied to a standard stimulus such as nail bed pressure.<sup>96</sup>

To date, however, there are no validated tests for the evaluation of pain symptoms in PDOC.

- > The Scale of Pain Intensity (SPIN) is a visual analogue scale designed to facilitate pain reporting for patients with communication and cognitive deficits,<sup>97</sup> which may potentially be used in some higher-level MCS patients with appropriate specialist facilitation, but with caution as it may generate false positives or negatives.
- > A number of assessment tools have been developed for patients with advanced dementia who cannot communicate their symptoms. These include the Abbey Pain Assessment tool<sup>98</sup> and the Pain Assessment in Advanced Dementia (PAIN-AD).<sup>99</sup>

In the context of PDOC, behaviours that are normally associated with pain may occur spontaneously as a result of reflex activity undamped by cortical inhibition, so the signs must be

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interpreted with caution. Further, changes associated with spontaneous or induced sympathetic over-activity (usually associated with hypothalamic damage) will give rise to signs similar to those induced by pain. Neither the Abbey tool nor the PAIN-AD is directly transferable to patients with PDOC, but the tool shown in Table 2.4 is a hybrid of the two adapted for this context. Since its initial publication in the 2013 UK guidelines, the tool has undergone preliminary validation.<sup>100</sup>

On a clinical level, it appears to work well as a structured framework for recording and monitoring behaviours that may denote the experience of pain in patients with PDOC and to have practical value for monitoring change in pain-related behaviours, for example in response to analgesia.

**Table 2.4 Behavioural pain assessment tool for patients in MCS\***

Items	0	1	2	Score
<b>Breathing independent of vocalisation</b>	Normal	Occasional laboured breathing Short periods of hyperventilation	Noisy laboured breathing Long periods of hyperventilation	
<b>Negative vocalisation</b>	None	Occasional moaning or groaning	Loud moaning or groaning Crying	
<b>Facial expression</b>	Smiling or inexpressive	Sad, frightened, frown, mild facial grimacing	Marked facial grimacing in response to presumed painful stimuli	
<b>Body language</b>	Relaxed/ calm	Tense Fidgeting	Rigid Marked tonal posturing	
<b>Consolability</b>	No need to console	Distracted or reassured by voice or touch	Unable to console, distract or reassure	
<b>Physiological change</b>	Normal	Mild increase in vital signs (temperature, pulse, BP etc.)	Marked increase in vital signs, or sweating, flushing/pallor	
<b>Presence of painful conditions</b>	None	Mild changes, eg marked skin, previously healed injuries, mild contractures	Marked changes eg broken skin, active arthritis or heterotopic ossification, severe arthritis/contractures	
<b>Total</b>				

\* Developed on the Regional Rehabilitation Unit, Northwick Park Hospital.<sup>100</sup> BP = blood pressure

### Mood

Mood assessment is similarly challenging. There is no literature addressing the assessment of mood specifically in patients with PDOC, so the following information represents opinion only.

The RCP has published concise guidance on evaluation of mood in patients with acquired brain injury,<sup>101</sup> but again the overlap between signs of low mood and deficits arising from the brain injury itself tends to confound evaluation.

- > The Depression Intensity Scale Circles is a visual analogue scale analogous to the SPIN<sup>102</sup> which again may be used in some patients with higher-level MCS with appropriate specialist facilitation, but again with caution as it may generate false positives or negatives.
- > For those with no communication ability, the guidance recommends use of the Signs of Depression Scale<sup>103</sup> as a brief screening tool to record features that may be associated with low mood. Two of the items ('lethargy/reluctance to mobilise' and 'needing encouragement to do things for him/herself') are clearly inappropriate for patients with PDOC. However, the remaining four items may have relevance in this context, and their recording at least encourages staff to be aware of the possibility of low mood.

The use of antidepressants is controversial in this context. Although depression is a recognised complication of brain injury, it is frequently not responsive to medication. Moreover antidepressant medication may also have unwanted effects (including sedation and lowering the threshold for seizure activity) and there are conflicting reports of its effect on neuroplasticity.

Clinical teams should be vigilant to the possibility of depression which can also contribute to misdiagnosis. If medication is considered it should be used in line with the RCP guidelines.<sup>101</sup> These include a period of watchful waiting and regular formal review of mood (eg using the above Signs of Depression Scale). If there is no clear evidence of response within 4 weeks of starting the medication it should be withdrawn. Similarly, all courses of antidepressant medication should be time-limited, with a clear endpoint (maximum 6 months) after which medication should be gradually weaned off and withdrawn.

### Signs of Depression Scale in PDOC

Does the patient sometimes look sad, miserable or depressed?	Yes / no
Does the patient ever cry or seem weepy?	Yes / no
Does the patient seem agitated, restless or anxious?	Yes / no
Does the patient seem withdrawn, showing little interest in the surroundings? (This may include evidence of deliberate withdrawal from interaction, eg eye closure when approached by staff)	Yes / no
<b>(Score 1 for 'yes' and 0 for 'no')</b>	<b>Total score</b>

## 2.7 Long-term monitoring and repeat evaluation

**Repeat clinical evaluation over time is required for clinical monitoring, treatment planning and *best interests* decision-making.**

Family members and care staff should be vigilant for signs of improving awareness and responsiveness. Key features that they may be advised to look for are shown in Box 2.1.

### Box 2.1 Features of responsiveness for families and care staff to look for

- 1 Do they show localising signs?
  - > eg move or look towards a specific stimulus (eg a sound)
  - > or follow people with their eyes as they move around the room?
- 2 Do they discriminate between different people?
  - > eg show preferential interaction with family or certain members of staff.
- 3 Do they make purposeful movements?
  - > Do they reach out for objects?
  - > Do they move appropriately in respond to command?
- 4 Do they indicate yes/no?
  - > eg by gesture, eye-pointing blink etc.
- 5 Do they show meaningful facial expressions?
  - > eg smile in response to a joke and cry / grimace in response to non-somatic stimuli appropriately (eg hearing bad news).

A more detailed list of screening items that the family and care staff may record is given in electronic Annex 2e at [www.rcplondon.ac.uk/pdoc](http://www.rcplondon.ac.uk/pdoc).

The observed behaviours may be mapped on to the CRS-R (for international comparison) and/or WHIM to observe for trends of change over time.

**Formal clinical re-evaluation** for the purposes of treatment planning and *best interests* decision-making, should be undertaken at 6 and 12 months post-injury and annually thereafter until the patient either dies or emerges from PDOC. A summary of the key timepoints for evaluation of patients in VS and MCS is shown in Fig 2.1.

As noted in Section 1, the diagnosis of VS or MCS should only be made by an appropriately experienced assessor, using formal diagnostic tools applied on repeated occasions over an appropriate period of time in conjunction with a detailed clinical neurological assessment. Follow-up evaluation should be undertaken by an appropriately skilled assessor, but it may be based on information gleaned from interviews with family members, carers and treating professionals. The CRS-R should be used as the primary tools for documenting change over time.

When a patient is diagnosed as being in 'chronic' or 'permanent' VS/MCS, a formal evaluation (see electronic [Annex 2f](#) for pro forma) should be signed by a consultant physician expert in PDOC who meets the criteria set out in [Annex 2b](#).

### Late assessment of PDOC in long-term care settings

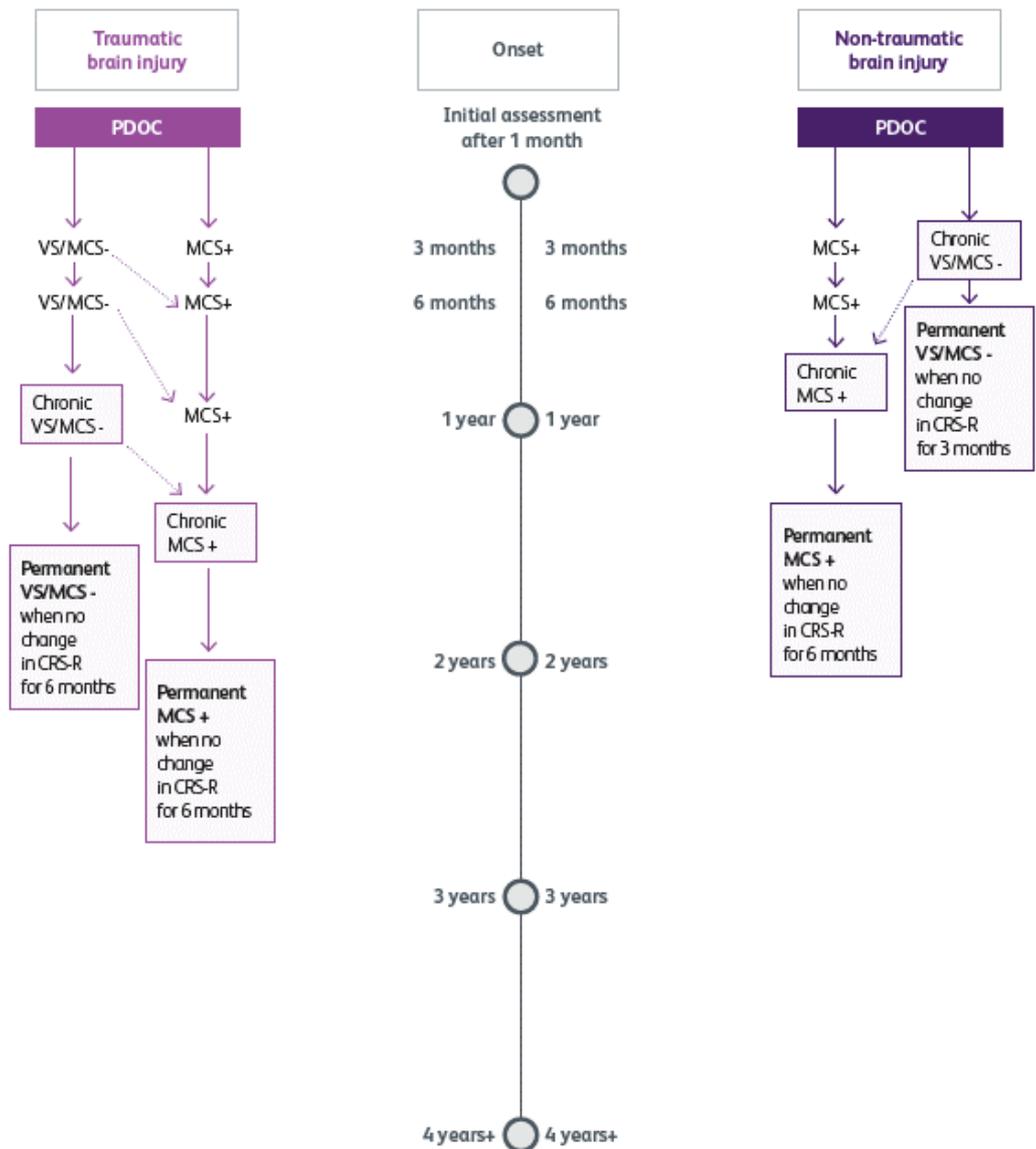
Ideally, all patients who remain in PDOC more than 4 weeks following sudden onset severe brain injury should undergo a period of detailed evaluation in the first few months. However, many patients in PDOC (VS/MCS) who are in long-term nursing home care have never had a formal assessment of their level of consciousness according to these guidelines. Many such patients have been in PDOC for many months (or even years) and the passage of time has already clarified the potential for spontaneous recovery.

It is still necessary to conduct an assessment in order to understand their level of awareness of themselves or their environment (in particular their experience of any pain/ distress) for the purposes of clinical management and to inform *best interests* decision-making regarding their ongoing care. However, it would rarely be appropriate at this stage to move them back into a specialist assessment centre for this purpose. Instead assessment may be conducted by a recognised PDOC Assessor or Expert PDOC Physician on an outreach basis in the context of their living environment (using on-site experience and expertise if this is available). The experience and expertise of such assessors becomes all the more relevant (refer to electronic [Annex 2b](#)).

The assessment should include:

- 1 Evaluation of the pre-requisites for diagnosis:
  - > confirmation that the neurological diagnosis (nature and extent of brain damage) is compatible with PDOC and does not suggest an alternative explanation of the (apparent) clinical state
  - > medication review
  - > exclusion of remediable causes (including imaging if this has not yet been done)
  - > clinical assessment of the primary sensory pathways (if there is no auditory or visual startle the patient may be both deaf and blind in which case assessment is challenging and may require admission to a specialist centre).
- 2 Assessment of awareness / responsiveness:
  - > assessment should be conducted under the supervision of an outreach PDOC assessor
  - > ideally there should be at least six CRS-R (and/or WHIM) scores carried out by the nursing staff or local rehabilitation team
  - > if not possible, the assessment may be conducted through structured interview with staff and family members using the CRS-R (phone/interview questionnaire)<sup>104</sup> or WHIM as a framework for recording behaviours
  - > in cases of significant uncertainty that could impact on a serious treatment decision (eg widely fluctuating MCS or a possible trajectory towards recovery), a brief admission to a PDOC centre may be required.

Fig 2.1 Key timepoints for evaluation of patients in VS, MCS-minus and MCS-plus



The prognosis for recovery of MCS-minus (MCS-) is generally similar to VS. The timing for assessment for a diagnosis of permanent MCS+ will depend on:

- > the nature and severity of the injury
- > any observed trajectory to improved responsiveness on serial testing.

Permanent VS/MCS should only be diagnosed by a PDOC specialist, based on serial assessment of the CRS-R over 6 months. Best interests discussions should not, however, be delayed until VS/MCS is diagnosed as 'chronic' or 'permanent', but should take place whenever a treatment decision is made.

This type of abbreviated assessment may also be relevant where life expectancy is significantly shortened (eg by age or presence of comorbidities) such that the patient may be expected to live >1 year but not more than 2–3 years (ie they fall between category 2 and categories 3–4 in Table 4.2). Electronic Annex 2g provides further detail on application of the tools by interview.

## 2.8 National PDOC registry for clinical monitoring and evaluation

As yet there is no consistent information on long-term outcomes for patients with PDOC in the UK. Systematically collected longitudinal data is required to identify patients with PDOC, and to monitor/track them through the course of their condition.

The GDG recommends the establishment of a national registry and agreed minimum dataset for the collection of a national cohort of longitudinal outcome data for all patients in PDOC. This recommendation has been endorsed by the BMA/RCP/GMC guidance.<sup>4</sup>

All patients who are in PDOC (VS or MCS) at the end of their initial assessment should be entered into the registry, and reviewed at least annually until either they emerge from PDOC or die.

The International Brain Injury Association Special Interest Group for Disorders of Consciousness is in the process of developing a core minimum dataset to be collected for international comparison. The GDG recommends that, so far as reasonably possible, the UK PDOC dataset should be aligned with the international dataset. The specific data items will need to be reviewed over time as that dataset develops

In the meantime, the core dataset of information that should be recorded at each annual review is listed in Box 2.2

The database should include the results of any formal assessments that have been undertaken (WHIM, CRS, SMART etc).

The registry should also include an up-to-date list of registered Expert PDOC Assessors and Consultant Physician Experts in PDOC who are able to provide a diagnosis of permanent VS/MCS and/or a second opinion on best interests. Electronic [Annex 2b](#) includes a registration form designed to confirm the relevant qualifications.

Recommendations for procurement and provision of the national database are addressed in [Section 6](#). Updates on development of the register and details of how and where to register patients once the database is established will be available on the UKROC website: [www.csi.kcl.ac.uk/ukroc.html](http://www.csi.kcl.ac.uk/ukroc.html).

### Box 2.2 Core data items to be collected at each annual review

- > Age
- > Aetiology – trauma, hypoxic, vascular (intracranial haemorrhage / infarct / subarachnoid haemorrhage), other
- > Time since onset
- > Clinical level of consciousness – VS, MCS-, MCS+
  - Based on the CRS-R – done serially at least 5 times in the early stages
  - Or by follow-up phone interview using a structured questionnaire
- > Measure of functional ability – Disability rating scale (or FIM)
- > Basic care
  - Tracheostomy
  - PEG/NG feeding
- > Clinical complications
  - Infections, seizures, parasympathetic hyperactivity
  - (spasticity, heterotopic ossification, endocrine)
- > Record of *best interests* discussion
  - Is it still in the patient’s best interests to receive life-sustaining treatment?
  - Is a ceiling of treatment plan in place? If so, what?

## Section 2 Assessment and diagnosis: Summary of recommendations

Recommendation	Grade
<p><b>2.1 Referral for specialist assessment</b></p> <ul style="list-style-type: none"> <li>&gt; Following severe acute onset brain injury, patients who remain in a state of disordered consciousness for more than 4 weeks should be referred to or transferred to a unit specialising in the multidisciplinary assessment/management of PDOC, for detailed clinical evaluation.</li> </ul>	E1/2
<p><b>2.2 Exclusion of treatable causes of PDOC</b></p> <p>Assessment should include the following to identify the cause of the brain damage and rule out treatable causes of PDOC:</p> <ul style="list-style-type: none"> <li>a CT or MRI scan of the brain to exclude haemorrhage or hydrocephalus (if not already undertaken in the acute phase)</li> <li>b clinical evaluation to confirm that the primary somato-sensory, visual, auditory and motor pathways are intact</li> <li>c general investigation to exclude metabolic/infective disorders</li> <li>d review of medication to stop or reduce any drugs which could affect the level of consciousness, unless essential</li> <li>e if, and only if, sub-clinical seizure activity is suspected, EEGs or trial of anticonvulsant.</li> </ul> <p>If point b above suggests that one or more of the primary neurological pathways are not intact, standard EEG response to eye-opening, or evoked potentials to visual, auditory or sensory stimuli, may be used to investigate further. Other than this however, EEG does not form part of the standard clinical evaluation.</p>	E1/2
<p><b>2.3 Further imaging and investigation</b></p> <ul style="list-style-type: none"> <li>&gt; Once a patient is in PDOC, repeat imaging is not routinely required. However, brain imaging may still be necessary:             <ul style="list-style-type: none"> <li>– to exclude undiagnosed or new specific structural, operable causes of the state (for which a CT scan will usually suffice)</li> <li>– if justified to inform clinical decision-making or prognostication (for which an MRI scan may be preferable).</li> </ul> </li> <li>&gt; Ventriculo-megaly is expected in cerebral atrophy secondary to severe brain injury, but:             <ul style="list-style-type: none"> <li>– If there is good clinical reason to suspect that treatable hydrocephalus is affecting responsiveness, timely neurosurgical advice should be sought.</li> <li>– For this potentially high-risk group of patients, it is not appropriate to undertake invasive procedures such as high-volume CSF removal via a lumbar puncture in a rehabilitation setting. Such procedures should only be performed under direct neurosurgical supervision.</li> </ul> </li> </ul>	E1/2

Recommendation	Grade
<p><b>2.4</b>     <b>Diagnosis of PDOC (vegetative or minimally conscious state)</b></p> <p>The mainstay of diagnosis is clinical evaluation for evidence of localising or discriminating behaviours indicating awareness of self or the environment.</p> <p>Diagnosis of VS or MCS should be based on:</p> <ul style="list-style-type: none"> <li>&gt; Assessment by appropriately trained clinicians, experienced in PDOC: <ul style="list-style-type: none"> <li>– under suitable conditions</li> <li>– using validated structured assessment tools (see recommendation 2.6)</li> <li>– in a series of observations over an adequate period of time.</li> </ul> </li> <li>&gt; In conjunction with clinical reports of behavioural responses gleaned from: <ul style="list-style-type: none"> <li>– the care records</li> <li>– interviews with family members / care staff.</li> </ul> </li> </ul>	<p><b>RA</b> <b>E1/2</b></p>
<p><b>2.5</b>     <b>Involvement of families</b></p> <p>Families play a key role in the assessment of patients with DOC because patients may respond at an earlier stage to their families / loved ones.</p> <ul style="list-style-type: none"> <li>&gt; Families should be actively involved in the assessment and management of patients with DOC.</li> <li>&gt; Clinicians should work closely with the family members, explaining <ul style="list-style-type: none"> <li>– what behaviours to look for</li> <li>– how to distinguish higher-level responses from reflex activity.</li> </ul> </li> <li>&gt; Where appropriate, families may also be encouraged to use tools such as the WHIM or videos to record their observations.</li> </ul>	<p><b>E1/2</b></p>
<p><b>2.6</b>     <b>Structured tools for assessment of PDOC</b></p> <ul style="list-style-type: none"> <li>&gt; The CRS-R should be used as the primary structured tool for assessment of the level of consciousness</li> <li>&gt; In addition, one or more of the following tools may be used to provide complimentary information according to the needs and presentation of the patient: <ul style="list-style-type: none"> <li>– the WHIM</li> <li>– the SMART.</li> </ul> </li> <li>&gt; Whichever tool(s) is(are) used, assessment should be undertaken: <ul style="list-style-type: none"> <li>– under suitable conditions (see <b>Section 2</b>, and electronic <b>Annex 2c</b> at <a href="http://www.rcplondon.ac.uk/pdoc">www.rcplondon.ac.uk/pdoc</a>)</li> <li>– at several different times of day, including baseline behaviours at rest</li> <li>– during initial assessment in the first few months, post-injury assessment should be conducted at least 10 occasions over a minimum of 2–3 weeks (see below for later stage assessment).</li> </ul> </li> </ul>	<p><b>RA</b> <b>E1/2</b></p>

Recommendation	Grade
<p><b>2.7 Advanced imaging/electrophysiology</b></p> <ul style="list-style-type: none"> <li>&gt; It is not yet clear whether more sophisticated electrophysiology and brain imaging techniques (eg fMRI, PET, DTI) have any diagnostic or prognostic utility over and above expert clinical and behavioural assessment.               <ul style="list-style-type: none"> <li>– They do not form part of the standard assessment battery for PDOC at the current time, nor do they represent a ‘practicable step’ required by s.1(3) MCA 2005 to support a person’s capacity to make relevant decisions.</li> <li>– Further work is required to understand the relationship between these and the formal clinical evaluation tests.</li> <li>– In the meantime, they should be only applied in the context of a registered research programme and in conjunction with formal clinical evaluation as described in recommendation 2.4 above.</li> </ul> </li> </ul>	E1/2
<p><b>2.8 Use of stimulation</b></p> <p>Controlled stimulation provides the best opportunity to observe responses, but the following pragmatic advice is offered to optimise the patient’s environment:</p> <ul style="list-style-type: none"> <li>&gt; Staff and families should be mindful of hypersensitivity and fatigue, and avoid overstimulation.</li> <li>&gt; Stimulation should focus on pleasant sensations such as favourite music, familiar pets, gentle massage etc offered one at a time.</li> <li>&gt; Family/friends should be asked to control their visits to avoid sensory overstimulation – with only 1–2 visitors at a time, visiting for short periods.</li> </ul>	E1/2 RB
<p><b>2.9 Medications</b></p> <p>There is insufficient evidence to make formal recommendations with respect to the use of medication to enhance arousal/awareness, although emerging evidence from recent trials suggests that at least some patients may benefit from amantadine during the recovery phase.</p> <ul style="list-style-type: none"> <li>&gt; The decision of whether or not to try medication, and choice of agent is a matter for clinicians to decide, in conjunction with families, on the basis of the patient’s best interests, taking into account the balance of benefits and harms, and any emerging evidence for effectiveness.</li> <li>&gt; If the decision is made to prescribe medication, this should be on the basis of a therapeutic trial (A-B-A design), using a single agent at a time, with formal monitoring to observe the impact of the medication.</li> </ul>	RA E1/2
<p><b>2.10 Repeat evaluation</b></p> <p>Repeat evaluation may be required for clinical decision-making / treatment planning, and to inform <i>best interests</i> decision-making.</p> <ul style="list-style-type: none"> <li>&gt; Clinical re-evaluation for the purposes of treatment-planning should be undertaken at the following key timepoints:               <ul style="list-style-type: none"> <li>– at 6 months post-injury</li> </ul> </li> </ul>	E1/2

Recommendation	Grade
<ul style="list-style-type: none"> <li>- at 12 months post-injury</li> <li>- annually thereafter until they emerge from PDOC or die.</li> </ul> <ul style="list-style-type: none"> <li>&gt; Assessment may be based on information gleaned from structured interviews with family members, carers and treating professionals and should be mapped on to CRS-R (and/or WHIM).</li> <li>&gt; If and when a patient emerges from MCS, the operational parameters used to demonstrate this (as per Table 1.5) should be formally recorded in the notes, dated and signed by the responsible clinician.</li> <li>&gt; When a patient is confirmed as being in a permanent VS/MCS, the specialist PDOC assessor should complete and sign the form in electronic <a href="#">Annex 2f</a>.</li> </ul>	
<b>2.11</b> Late assessment of PDOC in long-term care settings	<b>E1/2</b>
<p>Patients with long-standing ('chronic') PDOC who have not yet had a formal evaluation still require assessment to establish their level of awareness for clinical management and to inform <i>best interests</i> decision-making regarding their ongoing care and treatment.</p>	
<p>To avoid unnecessary admission, outreach assessment may be conducted under the supervision of an experienced PDOC assessor and should include the following:</p>	
<ul style="list-style-type: none"> <li>&gt; Evaluation of pre-requisites for diagnosis: <ul style="list-style-type: none"> <li>- confirmation of nature and extent of original brain damage</li> <li>- medication review, exclusion of remediable causes and clinical assessment of primary sensory pathways.</li> </ul> </li> <li>&gt; Assessment of awareness/responsiveness: <ul style="list-style-type: none"> <li>- ideally at least six CRS-R (and/or WHIM) scores) carried out by the nursing staff or local rehabilitation team</li> <li>- failing that defined in the point above, a structured interview with family and care staff to complete the CRS-R base on reported behaviours identified over the previous month</li> <li>- if there is significant uncertainty about the level of awareness that could impact on a serious treatment decision, a brief admission to a PDOC centre may be required.</li> </ul> </li> </ul>	
<b>2.12</b> Other assessments: symptoms such as pain and depression	<b>RB E1/2</b>
<ul style="list-style-type: none"> <li>&gt; Clinicians should be aware that patients with PDOC may suffer from pain and depression, but be unable to report them.</li> <li>&gt; Careful attention should be paid to the prevention, management and monitoring of these symptoms – including the use of structured tools to screen for their presence, as described in <a href="#">Section 2.6</a>.</li> </ul>	
<b>2.13</b> National PDOC Registry	

Recommendation	Grade
<p>A care dataset and national clinical registry for PDOC patients is in the process of development. As soon as this is established:</p> <ul style="list-style-type: none"><li data-bbox="405 315 1369 383">&gt; All patients admitted for PDOC evaluation should be entered in the register, and the core dataset should be completed.</li><li data-bbox="405 389 1406 495">&gt; The review dataset should be collected at each clinical review, and the database updated at least annually, until either they either emerge from PDOC or die.</li></ul>	

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## Section 3

# Care pathway – acute to longer-term management

### 3.1 General principles of care

Many patients who have disorders of consciousness in the early stages after the onset of brain injury will regain consciousness and awareness and will recover sufficiently to require specialist neurological rehabilitation and may well return home to independent or semi-independent life.<sup>105</sup> It is therefore important to avoid preventable complications earlier in the pathway, which might prolong hospital stay and prolong active rehabilitation and may even reduce the eventual level of independence.

The need for adequate specialist neurological rehabilitation services has been widely acknowledged in many national documents (including NICE guidance<sup>106</sup> and the Department of Health policy on major trauma networks<sup>107, 108</sup>). For those who remain in PDOC, proper management will not only avoid the development of complications, but will also simplify and shorten the full assessment of their condition. However, it is recognised that the current level of provision of these services is insufficient to meet demand.<sup>109, 110</sup>

Patients with PDOC most commonly have sudden onset of catastrophic disability. They have complex needs for care and treatment (medical, nursing, therapies etc) requiring the highly specialist skills of a multidisciplinary team. As it is often unclear in the early stages which patients will and will not regain full consciousness, it is important that their early post-acute care is provided in a specialist rehabilitation setting where they can be fully assessed and an appropriate care programme put in place.

Although unable to participate in active goal-orientated rehabilitation, patients in PDOC require a coordinated multidisciplinary approach to disability management<sup>111</sup> delivered by staff with specialist training in the management of complex neurological disability, who also have the skills to assess and monitor their level of responsiveness (see [Section 2](#)). A further important role for the team is to provide practical information and emotional support for families, as well as to gather information from families to ensure appropriate *best interests* decision-making.

Once this initial stage is complete, it is usually appropriate to transfer patients to an appropriately skilled longer-term care setting, where they will continue to require a maintenance therapy programme and specialist monitoring to watch for signs of returning awareness.

Although every patient should be seen and assessed by a specialist PDOC service (directly commissioned by the NHS England), the majority of their care may appropriately be given outside such a service. This section is therefore of particular relevance to local commissioners (such as clinical commissioning groups (CCGs) in England) and to the relatively non-specialist services that often manage these patients, both in the early phases and often in the longer term.

A proportion of the guidance in this section is not specific to people in PDOC, but concerns general good clinical care. General principles and standards of care will be covered briefly with reference to other documents for further detail including:

- > *Rehabilitation following acquired brain injury: National clinical guidelines* (Royal College of Physicians, 2003)<sup>112</sup>
- > *Medical Rehabilitation in 2011 and beyond* (Royal College of Physicians, 2010)<sup>111</sup>
- > *The National Service Framework (NSF) for Long-Term Conditions*<sup>113</sup>
- > *BSRM standards for rehabilitation services, mapped on to the NSF for long-term conditions* (British Society of Rehabilitation Medicine (BSRM), 2009)<sup>114</sup>
- > *Specialist neuro-rehabilitation services: providing for patients with complex rehabilitation needs* (BSRM 2015)<sup>115</sup>
- > *Specialist Nursing Home Care for people with Complex Neurological Disability: Guidance to Best Practice* (BSRM, 2013).<sup>116</sup>

### 3.2 Pathway of care

The care pathway for patients with PDOC is outlined in Fig 3.1. The diagram illustrates the principles of care in five phases, although not all of these will necessarily apply in every case. The pathway is not linear – patients may move up and down it or enter it at different points.

#### Phase I: Acute care – hospital ward

Many patients who enter a state of PDOC will be under the care of a team that may rarely, if ever, be confronted with the problems associated with prolonged coma, VS or MCS. They will not have any specialist knowledge, and will not have specialist skills in management of complex neurological disability.

An early priority is assessment by a specialist in neurology or neurorehabilitation who has expertise in management of these complex patients:

- > to confirm the causation of DOC and identify any potentially reversible contributing factors
- > to identify whether the primary neurological pathways are intact, and advise on appropriate investigation in the case of any doubt (see [Section 2](#)).

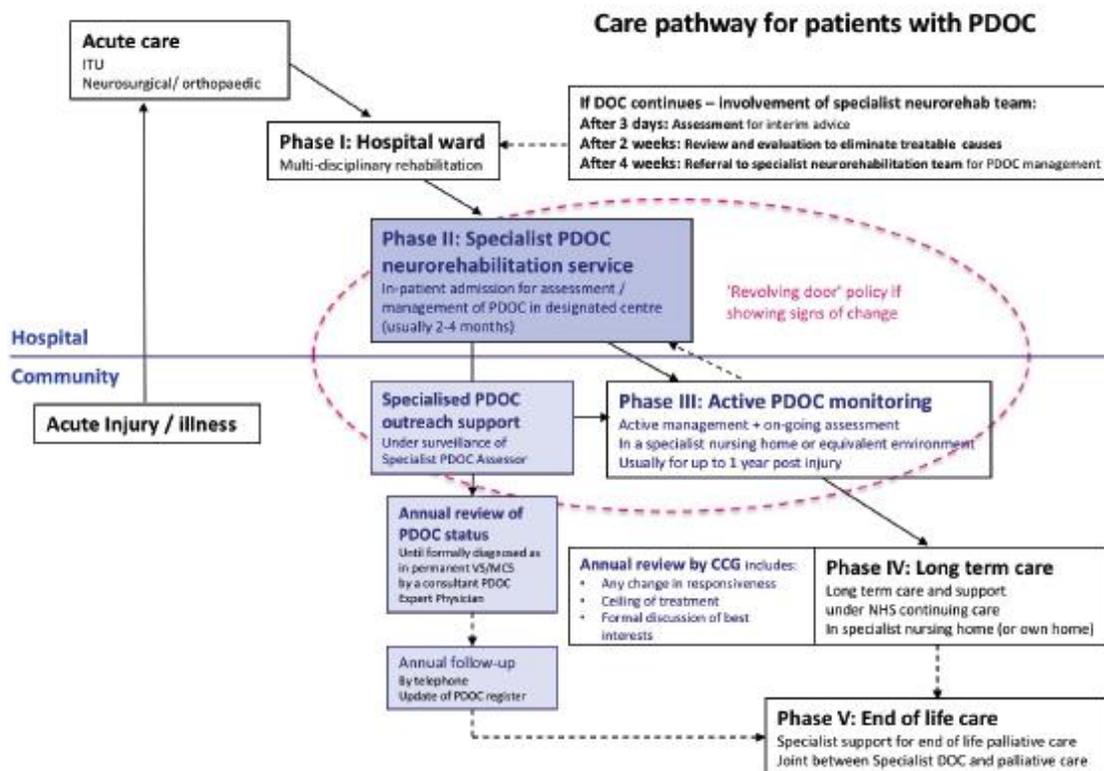
The specialist neurorehabilitation team should be involved from an early stage to support acute care clinicians in any of the task areas listed in Box 3.1, as many of these are needed while the patient remains in the acute care setting. As well as supporting their management in the acute stages of care, the specialist rehabilitation prescription should assist in directing patients down the appropriate pathway of ongoing care.

Within the major trauma pathway, current standards require that all severely injured patients should be seen by a consultant in rehabilitation medicine (RM) and a ‘*rehabilitation prescription*’ drawn up to guide their further rehabilitation on discharge from the major trauma centres.<sup>108</sup>

### Section 3 Care pathway – acute to longer-term management

For patients with complex needs (which includes patients in coma or PDOC following traumatic brain injury) the RM consultant should draw up a specialist rehabilitation prescription.<sup>117</sup> This process can be used to identify patients in PDOC and to expedite referral and transfer to a neurorehabilitation service with expertise in PDOC management. If rehabilitation prescriptions work in the trauma pathway there is no reason why they should not apply in the other acute pathways (eg neurosciences).

Fig 3.1 The care pathway for patients with PDOC



The care pathway for patients who remain in PDOC

\* These services are specialist elements of the PDOC service to be commissioned centrally by NHS England (see Section 6).

### Phase II: Sub-acute care – early proactive management

It is rarely appropriate simply to repatriate patients with DOC to a general ward setting. As in every other part of healthcare, it is important that a patient should be managed by a clinical team and service with the appropriate knowledge and skills. The most appropriate specialist service to be involved after the acute phase is the neurological rehabilitation service led by a consultant in rehabilitation medicine with experience in management of PDOC.<sup>111</sup>

As most neurorehabilitation services do not have sufficient experience or throughput to manage patients with PDOC, the GDG recommends that there should be a small number of designated specialist PDOC centres to build up a critical mass of expertise. However, these should have outreach facilities to support ongoing monitoring/assessment of patients closer to their own home (eg in local rehabilitation units or specialist nursing home facilities).

Key elements of the programme are listed in Box 3.1, and further detail on clinical management is given in electronic annexes 3a–d at [www.rcplondon.ac.uk/pdoc](http://www.rcplondon.ac.uk/pdoc).

The patient should remain under the care of the specialist neurological rehabilitation service until the management recommended above has been completed. Depending on how long it takes to stabilise the patient's medical condition and then to perform the appropriate assessments of responsiveness and set up the care programme, this will usually mean that a patient remains in the acute / post-acute rehabilitation setting for 2–4 months. Some patients, however, may require up to 6 months, especially if they are demonstrating a trajectory towards improved consciousness. For people whose life expectancy is significantly shortened by age, multiple comorbidities or frailty, such that they fall between category 2 and categories 3–4 (in Table 4.2, a shorter assessment may be more appropriate as described in Section 2.7.1).

A set of standardised objectives (to be used alongside more personalised goal setting) has been developed to assist with monitoring and outcome evaluation of these phase II programmes,<sup>118</sup> and will be incorporated into future versions of the UK Rehabilitation Outcomes Collaborative (UKROC) national clinical dataset. This is available for free download from the following website: [www.kcl.ac.uk/cicelysaunders/resources/tools/gas](http://www.kcl.ac.uk/cicelysaunders/resources/tools/gas).

A priority goal for the initial admission is often to support families in understanding the consequences of the patient's brain injury and likely future trajectory, and helping them to manage and come to terms with their own loss. In highly distressing circumstances, this is often another key factor to determine length of stay. Family members often benefit from both the intensive support from the clinical team and the opportunity to meet and network with other families who are facing a similar set of problems.

### *Best interests decision-making*

By definition, patients in PDOC lack the capacity to make decisions regarding their own care, and require these to be made for them on the basis on their best interests. While decision-making starts from the strong presumption that it is in the patient's best interests to prolong life, this has to be balanced against the likely benefits and harms of any intervention, taking into account the patient's likely wishes.

**Box 3.1 Phases I and II: Early proactive management of patients with PDOC**

The general management of patients with PDOC should follow the National Clinical Guidelines for *Rehabilitation following acquired brain injury* ([www.rcplondon.ac.uk/publications/rehabilitation-following-acquired-brain-injury-0](http://www.rcplondon.ac.uk/publications/rehabilitation-following-acquired-brain-injury-0)). More detail is given in annexes 3a–d. Every intervention should be given on the basis of the patient's best interests under the terms of the Mental Capacity Act 2005.

**The multidisciplinary goal-orientated programme of care should include:**

**a A 24-hour programme of care including:**

- > airway management, including tracheostomy care, management of secretions, ventilatory support if required
- > enteral nutrition and hydration per gastrostomy (or jejunostomy if gastric stasis or oesophageal reflux are problematic) – with adequate nutritional support to meet dietary requirements, including enhanced calorie take in the case of a hyper-catabolic state
- > management of oral reflexes (eg bite reflex, teeth grinding etc)
- > a suitable bowel and bladder management programme
- > suitable precautions to avoid pressure ulceration, including risk assessment, special mattress etc
- > positioning to manage posture avoiding contractures and maintaining skin integrity
- > supportive seating to offer a range of positions and allow assessment in a sitting position and again most importantly manage posture and maintain skin integrity.

**b Medical management of any complications arising from severe brain injury including:**

- > further investigations to determine the cause of brain injury and exclude complications, eg hydrocephalus, diabetes insipidus and other endocrine disturbance, seizures, visual and hearing impairments
- > management of sequelae including autonomic dysfunction ('sympathetic storming' or 'paroxysmal sympathetic hyperactivity'), pain, spasticity, intercurrent infections, thromboprophylaxis etc
- > medical surgical management of any other health conditions (eg fractures, blood pressure control).

**Specific requirements for patients with PDOC include the following:**

- > registration of the person on the national clinical database (see [Section 2](#))
- > detailed clinical assessment of the level of interaction and responsiveness, which should take place throughout this period
- > a formal structured assessment of the level of responsiveness using one of more of the recommended tools in [Section 2](#) (at minimum the CRS-R), which should be performed once their medical condition has stabilised
- > information given to the family regarding diagnosis and expected prognosis, so far as this can be determined, with advice about possible future care and decision-making
- > formal *best interests* meetings, which should be undertaken as required and involving the family (and/or other representatives, including any Welfare LPA, Welfare Deputy or Independent Mental Capacity Advocate (IMCA) as appointed) to address:
  - decisions regarding the appropriateness of resuscitation in the event of a cardiorespiratory arrest
  - any other key decisions regarding treatment and care, including life-sustaining measures (such as antibiotics), long-term care arrangements etc (see [Sections 4 and 5](#)).
- > early discharge planning, including a formal meeting with the family (and/or other representatives) and healthcare commissioners, to discuss place of care and to start to put in place the appropriate arrangements for funding (usually through an application for NHS Continuing Care).

New guidance from the BMA/RCP/GMC<sup>4</sup> emphasises the responsibility of clinicians not simply to start or continue treatment by default, but to consider the patient's best interests for each and every intervention. *Best interests* discussions should therefore start from an early stage and continue throughout the care pathway.

- > Family members should be informed of the range of possible outcomes and invited to discuss the patient's prior expressed values, beliefs, wishes and feelings in relation to those.
- > When family or friends spontaneously raise concerns about whether or not the patient would want medical treatments, this should be taken seriously and should prompt *best interests* decision-making as a matter of priority.

See Sections 4 and 5 for more detail on decision-making.

Some interventions may simply not be on offer. Others may be offered, but the patient might or might not have wished to accept them. It is appropriate to discuss and agree any plans for escalation or ceiling of treatment at each stage in the pathway (see Sections 4 and 5 for more detail). Continued life-sustaining treatment (including CANH) should only be offered on the basis that it is clinically appropriate and should only be provided in the patient's best interests and in line with their likely wishes. Although discussions start from the premise that it is in the patient's best interests to preserve life, as noted above it is the giving (rather than the withdrawing) of treatment than needs to be justified and the reasons for this recorded (see Section 4 and 5 for more information).

### Phase III: Continued active management with specialist PDOC monitoring

Patients remaining in VS or MCS are not in a position to participate in formal goal-orientated rehabilitation. Once their medical condition is stabilised, and a detailed clinical assessment of their needs has been completed as outlined above, they will usually require a period of active management and ongoing specialist assessment until either they recover sufficiently to benefit from a transfer to a specialist rehabilitation unit or it becomes clear that they are likely to remain in VS or MCS – usually 6 months to 1 year post-injury.

Some essential elements of the care package for this period of active healthcare management and ongoing assessment must include an appropriate maintenance therapy and stimulation programme, as set out on Box 3.2.

Electronic [Annex 2c](#) provides specific advice for care staff on optimising conditions for interaction and [Annex 2e](#) provides a checklist for recording behaviours that are observed by family members and care staff: see [www.rcplondon.ac.uk/pdoc](http://www.rcplondon.ac.uk/pdoc).

### Place of care and treatment

Although families are often understandably keen for the patient to come home as soon as possible, it is rarely possible to provide the level of nursing care and expertise that is required at this stage in the context of the home environment. Placement in a formal care setting is usually required on either an interim or permanent basis.

### Box 3.2 Some essential elements of phase III active management and monitoring

- > **Physical care** – postural management, prevention of contractures, tracheostomy management (if needed) etc
- > **Review of long-term enteral feeding, swallowing therapy**
- > **An appropriate programme of stimulation** and opportunities for involvement in social activities, especially for patients with a trajectory towards increased awareness
- > **Training for staff to look for evidence of localising or discriminatory responses** and to use tools such as the CRS-R and/or WHIM as a framework to record any observed responses, working under the supervision of a specialist PDOC assessor (see Section 2)
- > **Where necessary, support for communication and interaction**, including the provision of appropriate communication or environmental control aids and training for care staff to provide opportunities for interaction

Placement will usually be in an appropriate specialist nursing home that caters specifically for the needs of adults with complex neurological disability. It is essential that the chosen interim placement has the appropriate staffing expertise and facilities to manage patients in VS/MCS and provide the programme elements listed in Box 3.2. Standards for specialist nursing homes are published by the British Society of Rehabilitation Medicine (BSRM).<sup>116</sup>

Currently these specialist facilities are relatively thinly spread in the UK. A number of factors may influence the choice of facility including:

- > whether it is anticipated to be a short- or long-term placement
- > geographic proximity to family / other visitors
- > the patient's specific needs for skills/facilities/equipment, which may be available in one setting but not another.

If the family is closely involved, ease of access for family visiting is often the key factor to govern choice of placement. Depending on the circumstances, however, families are often willing to travel quite long distances to ensure that the patient receives the best quality care.

- > Families should be involved in discussions regarding suitable placement options and their preferences should be taken into account.
- > The final choice of placement will take into account the wishes of the family, but ultimately be determined by the clinical needs of the patient on the basis of their best interests.
- > Non-specialist nursing homes should be considered only if they can demonstrate that they can meet the needs of the patient and, at the same time, offer an advantage in proximity to the family. They should not be chosen simply because they are a cheaper option.

If anyone has been officially appointed as the patient's Welfare LPA or Deputy and their authority covers placement issues, it is essential that they are involved in any *best interests* meeting since it is they who decide place of care.

If there is no family/close friend, or where family members are deemed ‘inappropriate to consult’, then the MCA 2005 requires that an IMCA must be instructed to represent the person in placement decisions. The report they provide will be part of the *best interests* decision. In practice there may be little choice in the matter if there is only one suitable nursing home available and, in an urgent case, s38(3)(b) allows for the placement move to take place on an urgent basis with no need to wait for IMCA appointment and the appointment can take place after the move (s38(4)). Nevertheless, their involvement is essential, and clinical teams should be mindful for the need for timely referral.

### Ongoing specialist PDOC surveillance and monitoring

The overall responsibility for holistic patient care for patients in a non-hospital setting lies primarily with the patient's GP. However, there should be a nominated consultant in neurorehabilitation or neurology, responsible for overseeing the review process. All patients in PDOC should remain under surveillance at least until they are diagnosed as being in permanent VS/MCS (see [Section 2](#)).

Patients in continuing or chronic VS or MCS should remain under active surveillance by a specialist PDOC service. They should be reviewed at least annually to provide specialist advice as necessary and to monitor for any significant change in the level of responsiveness or clinical condition.

During this active monitoring phase, reviews should be conducted under the supervision of a specialist PDOC assessor, usually working on an outreach basis in conjunction with the local clinical team (see [Section 2.7](#) and [Annex 2b](#)). At a minimum, this should include application of the CRS-R, and data should be passed to the national register, as and when this has been developed (see [Section 2](#)). These reviews will normally take place within the patient's place of residence/placement, unless the issues are highly complex or multi-faceted and so better managed through a short-term inpatient admission (see below).

Annual review should include a consideration and discussion of best interests. Appropriate ceiling of treatment arrangements should be discussed and agreed at each annual review. Treating teams and commissioners should not simply continue treatment because it is the easiest option. Family members must be given ongoing opportunities to discuss withdrawal of life-sustaining treatment, including the practical, legal and emotional aspects. It is the duty of the individual with overall responsibility for the patient's care to raise the issue, rather than waiting for family members to do so. (See [Section 4](#) for more detail).

### Permanent VS/MCS

If the patient remains in chronic VS/MCS for more than 6 months without any evidence of a trajectory towards improvement, they may be diagnosed as being in permanent VS/MCS. This diagnosis should be confirmed by an Expert PDOC Physician who completes the form in [Annex 2f](#), and this information entered in the national registry.

At this stage, the reasonable hope of recovery is no longer applicable and the balance of benefits and harms swings further away from active treatment.

Within 4 weeks of this diagnosis a formal *best interests* discussion should take place between the family, the treating team and anyone else (such as a Welfare LPA) with decision-making powers (see [Section 4](#)) to consider whether continued life-sustaining treatment is in the

patient's best interests in the context of a shared understanding that it is now highly improbable that the patient will recover consciousness. It is usually appropriate at least to draw up a ceiling of treatment plan if one is not already in place.

If it is decided that it is in the patient's best interests to continue life-sustaining treatment, this should be recorded along with the reasons for this decision. The CCG, treating team and family will need to agree: a) where this will be managed; and b) how it will be funded – especially as patients in permanent VS/MCS may not automatically qualify for 100% NHS-funded continuing healthcare (see [Section 6](#)). These arrangements will be reviewed at least annually and further *best interests* discussions should be included in each annual review.

Patients in permanent VS/MCS no longer require formal annual review by a specialist PDOC assessor, although it is good practice to conduct a brief annual follow-up interview (eg by telephone): a) to confirm with the family/care staff that there has been no change in the patient's condition or responsiveness; and b) to enter this information on the register.

If there is any suggestion that their level of responsiveness has changed, this should be confirmed using the telephone version of the CRS-R (see [Annex 2g](#)), and if necessary a further face-to-face assessment.

#### Revolving door policy

As noted above, not all patients travel in linear fashion down the care pathway. Early discharge from post-acute rehabilitation relies on appropriate facilities being available in the community, and also the ability to operate a 'revolving door' policy to offer further planned or unplanned admission, in accordance with patient needs.

Reasons for requiring readmission to the specialist neurorehabilitation unit may include:

- > improvement in the patient's level of responsiveness to an extent where he or she would benefit from a specialist goal-orientated rehabilitation programme
- > the placement proves to be unable to meet the care needs satisfactorily, requiring care needs to be redefined and a suitable alternative found
- > a specific problem that requires admission for disability management (eg severe spasticity, marked postural difficulties, skin pressure ulceration, de-cannulation of tracheostomy) or medical/surgical management
- > the patient has reached a critical point in the decision-making process but there is uncertainty about their condition and/or prognosis, which requires a short admission to assess formally the level of awareness, to conduct formal *best interests* decision-making meetings and to agree the way forward in discussion with the family and treating team.

#### Phase IV – Long-term care

Long-term care should be provided in an appropriate setting, which may be in the patient's own home with family, but is more usually arranged in a nursing home setting; living alone with a care team is not appropriate.

Long-term nursing home care should be delivered in a setting that has appropriately skilled staff to manage the needs of patients with PDOC, including management of:

- > physical disability, including postural management and as appropriate, maintenance therapy (including management of spasticity and prevention of contractures/pressure sores etc), medical surveillance etc

- > enteral feed and tracheostomy management
- > appropriate stimulation and ongoing assessment of behavioural responses, albeit at low level
- > support for families.

If the nursing home does not have its own therapy team, arrangements should be in place to provide a maintenance therapy programme through visits from the local community rehabilitation team or an alternative spot-purchasing arrangement by the CCG.

As for interim care, long-term placement should take account of the needs of the family and ease of access for visiting – especially in circumstances where the patient responds best to family members and appears to gain positive life experience from family visits. The longer the time since injury, the less likely it is that the patient will emerge, so at this stage the emphasis is more on maintaining quality of life than preserving function towards the expectation of future recovery.

### Long-term care in the home

As noted above, families are often keen for the patient to be placed at home, but often without any clear understanding of the enormity of the task of caring for them. Patients with PDOC have very intensive and specialist care requirements and it is rarely feasible or practical to provide care in the home setting unless one or more family members are dedicated to providing the role of lead carer. On the other hand, a small number of patients react so positively to family members and home life that care at home is agreed by all parties to be the best option.

Caring for an individual who has very limited ability to interact is a challenging task for non-family carers, and there are often practical difficulties including recruitment and retention of suitably trained care staff.

In the majority of cases, the patient's lack of awareness limits the extent of positive experience that may arise from being at home. Inevitably the household tends to revolve around their needs, which may be to the detriment of others (for example, children) in the home setting.

In many cases, a much better solution may be to provide the majority of care in a nursing home setting, but with the opportunity to spend short periods (usually daytime visits) at home. When planning these arrangements, factors to consider are:

- > travelling distance to and from the home and the length of time the patient can sit comfortably in a wheelchair / risk of pressure sores etc
- > access into the home, and to facilities within the home, in case of episodes of incontinence or if overnight stay is planned.

As in all other areas of care, the decision to arrange home care or home visits must be taken in the patient's best interest, based on the balance of benefits and risks.

### Short term readmission for intercurrent medical/surgical conditions

From time to time patients in VS/MCS may require short-term acute hospital admission for intercurrent illness or planned procedures. All such interventions should be undertaken with due regard to *best interests* decision-making and agreed escalation or ceiling of treatment plans.

The Resuscitation Council is currently implementing a process called ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) [www.respectprocess.org.uk](http://www.respectprocess.org.uk). This is a form of advance/anticipatory care planning, which creates personalised recommendations for a person's clinical care in a future emergency in which they are unable to make or express choices. It provides health and care professionals responding to that emergency with a summary of recommendations to help them to make immediate decisions about that person's care and treatment. Although primarily designed for people who are still able to make their own treatment decisions, this process may form a useful aid to implementing agreed ceiling of treatment plans.

It is important that patients' neurological needs continue to be met while they are in hospital. This will require liaison with their usual neurological care team, and the involvement of any family carers who are likely to be more familiar with their individual care needs. For some more complex elective procedures, it may be appropriate to arrange short-term admission to the specialist neurorehabilitation services, as opposed to a general ward where staff are unlikely to be familiar with their needs. This, however, will depend on the patient's needs and ease of access to the required acute services from within the specialist neurorehabilitation service.

### Phase V – End-of-life care

If the patient comes naturally to the end of their life or a decision is made to withdraw life-sustaining treatment, this should be accompanied by an agreed end-of-life care plan specifying where and how the care will be managed and delivered.

Complex *best interests* decision-making surrounding end-of-life care is a specialist area of practice. Details of recommendations for managing end-of-life and terminal care are included in [Section 5](#).

## 3.3 Support for families

People who remain unresponsive present great emotional and social challenge to others – especially to family members, but to others as well.

- > At one level it can seem that the person is 'in there', because they wake up and go to sleep; they may move and make noises spontaneously; and they often react to external stimuli.
- > But, at the same time, they do not initiate any communication or social interaction.
- > They appear unreactive to anything meaningful – or there may be doubt about this with those who care for/about them left unsure about whether or not there is a response.
- > They may also appear to be in pain or distress at times.

This unusual state is stressful for many reasons:

- > It challenges our normal understanding of people and their behaviour.
- > The family are under huge stress about how, and how often, to be at the bedside and worry about what their relative might be experiencing and their own role in supporting them. They:
  - often have to navigate uncertainty about the future, are dealing with a prolonged and exhausting rollercoaster of emotions and ricocheting between fear and hope
  - sometimes receive differing explanations and prognosis from the various medical and clinical teams involved

- cannot grieve their loss fully, yet they may not be able to expect a 'good outcome' (ie either a return to the pre-existing state or at least a return to some kind of demonstrable contentedness).
- > For some families, the state of existence of their loved one may be in contradiction to that person's prior expressed views on how he/she would want to live. Their inability to protect their loved one from this unwanted outcome can be a source of guilt, anger and distress.

Many families will have been informed during the early acute stage of injury that the patient is unlikely to survive. Once the patient has survived, apparently against all odds, miracles may seem, not only possible, but likely, and family members may see their loved one as a 'fighter' with a determination to recover which will overcome physiological obstacles. They may therefore have high expectations for full recovery, and be inclined to disbelieve less optimistic prognostication.<sup>119</sup> In addition, there is often genuine uncertainty about the patient's condition and prognosis until evaluation is complete, and it is important to keep open lines of communication and a free exchange of information as evaluation progresses and the picture clarifies.

It is critical to provide consistent support and information for the family and/or other people with strong emotional attachments, and to involve them closely (if they so wish) in decisions made in the patient's best interests (see [Section 4](#)).

All families should be offered support to encompass, as needed:

- > information, including:
  - explanation of the clinical state
  - the prognosis, including clear assessments of the 'best likely' level of recovery – and level of uncertainty (rather than simply focusing on whether consciousness might return)
  - discussion of available treatments, and investigations
  - a name identifying who is responsible for making serious medical decisions
  - clear explanation of the process of *best interests* decision-making and their own role within it
  - proposed management plan and timetable for review of *best interests* decisions.
- > emotional support
- > practical support, eg assistance with managing finances, housing, medico-legal issues etc.

Families should be supported to engage actively in the care programme if they so wish, and provided with tasks / activities that they can undertake with the patient, such as gentle massage / stretching, stimulating activities etc. It is important that they have the opportunity to contribute, and discuss, their observations of the patient's behaviours. They should not be left to try to make sense of possible responses alone. Nor should they be subject to well-meaning, but possibly misleading, comments, which emphasise the effect of their presence on the patient (for example, from staff who are keen to give immediate emotional support and comfort without sufficient understanding of the condition itself or the potential long-term effect of their comments).

They should be offered counselling and support at a stage when they are ready to receive this. However, they are often not ready to engage with this in the early stages, so the offer may need to be repeated. It is also important that such support is provided by professionals with an

understanding of PDOC and the different ways that people react to the diagnosis and its implications for the whole family.

Family members often gain support from being in contact with others who are / have been in a similar position. The management of patients with PDOC in centres with a critical mass of patients in the condition can be very positive. In addition, groups such as BIG – the Brain Injury Group ([www.braininjurygroup.org.uk/Pages/default.aspx](http://www.braininjurygroup.org.uk/Pages/default.aspx)) – that was developed as a support group for people who have loved ones with devastating brain injuries, can also provide welcome peer-group support for families. They may also like to gain information and hear and see the experiences of other people confronting similar situations online via Healthtalk.org – a free and online resource for families: [www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/overview](http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/overview).

## Section 3 Care pathway – acute to longer-term management: Summary of recommendations

Recommendation	Grade
<p><b>3.1 Early referral for advice on disability management</b></p> <ul style="list-style-type: none"> <li>&gt; As with all patients with severe brain injury, patients who continue to have a DOC after 3 days should be assessed by a specialist neurorehabilitation team for interim advice on management of neurological disability.</li> <li>&gt; Those remaining in DOC should have a specialist rehabilitation prescription to guide their ongoing care after leaving the acute care services.</li> </ul>	E1/2
<p><b>3.2 Specialist neurological evaluation</b></p> <ul style="list-style-type: none"> <li>&gt; Every patient whose Glasgow Coma Scale (GCS) score remains <math>\leq 10/15</math> two weeks after onset of coma should have a specialist neurological evaluation within 3 weeks of onset to:               <ul style="list-style-type: none"> <li>– confirm the causation of DOC and identify any potentially reversible contributing factors</li> <li>– identify whether the primary neurological pathways are intact, and advise on appropriate investigation in the case of any doubt.</li> </ul> </li> </ul>	E1/2
<p><b>3.3 Referral for specialist management by the neurorehabilitation team</b></p> <ul style="list-style-type: none"> <li>&gt; Every patient whose GCS remains at <math>\leq 10/15</math> at 4 weeks should have active and continuing involvement of a specialist neurological rehabilitation service, led by a consultant in rehabilitation medicine.</li> </ul>	E1/2
<p><b>3.4 Transfer to phase II specialist PDOC care</b></p> <p>It is not appropriate simply to repatriate patients with PDOC to a general ward setting.</p> <ul style="list-style-type: none"> <li>&gt; As soon as the patient’s medical condition allows, patients with continuing PDOC should be transferred to the care of a specialist neurorehabilitation team               <ul style="list-style-type: none"> <li>– preferably to a unit specialising in the assessment/management of PDOC.</li> </ul> </li> </ul>	E1/2
<p><b>3.5 Exchange of information with the family</b></p> <p>There should be regular contact between the treating team and the family to provide support and two-way exchange of information.</p> <p>The family should be offered support to encompass, as needed:</p> <ul style="list-style-type: none"> <li>&gt; information including:               <ul style="list-style-type: none"> <li>– explanation of the clinical state and its prognosis</li> <li>– proposed management plan for investigation and treatment</li> </ul> </li> <li>&gt; emotional support</li> <li>&gt; practical support, eg with managing finances, medico-legal issues etc.</li> </ul>	E1/2

Family members should also have the opportunity to be involved as closely as possible in decisions made in the patient's best interests (see below).

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### 3.6 Management programme

E1/2

The general management of patients with PDOC should follow the *Rehabilitation following acquired brain injury: National clinical guidelines* ([www.rcplondon.ac.uk/publications/rehabilitation-following-acquired-brain-injury-0](http://www.rcplondon.ac.uk/publications/rehabilitation-following-acquired-brain-injury-0))

- > The patient should have a coordinated programme of care delivered by a multidisciplinary team including:
  - a 24-hour programme of care as detailed in **Section 3**, including supportive seating to maximise the potential for interaction
  - medical management of any complications arising from severe brain injury
  - formal assessment of the level of interaction and responsiveness as described in **Section 2**.
  
- > Early discharge planning, including a formal meeting with the family and healthcare commissioners to discuss place of care, and start to put in place the appropriate arrangements for funding.
  
- > Patients in PDOC are not expected to make changes that are reflected in the standard outcome measures. Instead outcome from these programmes should be evaluated using goal attainment scaling (GAS) using the structured goal-set incorporated into the UKROC database  
[www.kcl.ac.uk/cicelysaunders/resources/tools/gas](http://www.kcl.ac.uk/cicelysaunders/resources/tools/gas).

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### 3.7 Best interests decision-making

E1/2

In accordance with the Mental Capacity Act 2005, unless there is a valid and applicable advance decision, all treatments must be given on the basis of the patient's best interests and in line with their likely wishes.

- > While decision-making starts from the premise that it is in the patient's best interests to preserve life, no treatment or intervention should simply be started or continued by default.

Formal *best interests* meetings should be undertaken from an early stage and involve the family and other appointed patient representatives (eg Welfare LPA, Deputy or IMCA) to address:

- > decisions regarding the appropriateness of resuscitation in the event of a cardiorespiratory arrest
- > emergency measures such as escalation to intensive or high dependency care, antibiotics etc.
- > long-term treatments including:
  - preventative measures (eg thromboprophylaxis, tracheostomy etc)
  - replacement support for organ failure (eg insulin, dialysis etc)
  - CANH.

(See Sections 4 and 5 for further information)

An agreed ceiling of treatment plan should be drawn up at each stage of the pathway, and kept under regular review.

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### 3.8 Length of programme in specialist assessment centre E1/2

- > The length of time in the specialist centre should depend on the individual's needs, and is dictated by the time taken to complete the tasks in recommendation 3.6.
- > The rate of adjustment of the family is often another key factor.
- > In most cases 2–4 months should be sufficient, but occasionally up to 6 months, especially where there is a trajectory towards improved awareness.

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### 3.9 Transfer to phase III care E1/2

Patients in VS or MCS are not able to participate in goal-orientated rehabilitation.

- > Once their medical condition has stabilised and a detailed clinical assessment of their needs has been completed:
  - patients should be managed in a placement outside of the acute / post-acute setting, until it becomes clear that they are likely to remain in VS or MCS – usually 6-months to 1-year post-injury
  - this will usually be an appropriate specialist nursing home, which caters specifically for the needs of adults with complex neurological disability.

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### 3.10 Requirements of a phase III placement E1/2

- > The specialist nursing home must have the appropriate staffing expertise, equipment and facilities to manage patients with complex neurological disability, specifically those in VS/MCS.
  
- > This includes the provision of:
  - an appropriate maintenance therapy programme to manage their physical disability
  - an appropriate environment to provide controlled stimulation and encouragement for interaction,
  - ongoing monitoring of their level of responsiveness.

(NB: see below and also *Specialist nursing home care for people with complex neurological disability: guidance to best practice*, BSRM, 2013)<sup>116</sup>

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### 3.11 Family involvement in choice of placement E1/2

If the family is closely involved, ease of access for family visiting is often a key factor to govern the choice of placement.

- > Families should be involved as closely as possible in discussions regarding suitable placement options and their preferences should be taken into account. This is not only important for caring reasons, but is a key part of making *best interests* decisions, which are a legal requirement as defined by the Mental Capacity Act 2005.

- > The final choice of placement will take into account the wishes of the family, but ultimately be determined by the clinical needs of the patient on the basis of their best interests.
- > Non-specialist nursing home options should be considered only if they can demonstrate that they meet the patient's needs and, at the same time, offer an advantage in proximity to family. They should not be chosen simply because they are a cheaper option.
- > If anyone has been officially appointed as the patient's Welfare LPA or Deputy and their authority covers placement issues, they may be the decision-maker, and it is essential that they are involved in any meeting to decide place of care.
- > If there is no family or they are deemed '*inappropriate to consult*' then an Independent Mental Capacity Advocate (IMCA) must be instructed to represent the person and the report they are required to provide will be part of the *best interests* decision.

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### 3.12 Longer-term care

E1/2

- > Longer-term care should be provided in an appropriate setting, which will usually be a specialist nursing home.
  - Occasionally patients with PDOC may be managed in their own home, but it should be noted that they have very intensive and specialist care requirements. It is rarely feasible or practical to provide care in the home setting unless one or more family members is dedicated to providing the role of lead carer.
- > Nursing home care should be delivered in a setting that has appropriately skilled staff to manage the needs of patients with PDOC, including management of:
  - physical disability, including maintenance therapy for tone/postural management (including management of spasticity and prevention of contractures/pressure sores etc), medical surveillance etc.
  - enteral feed and tracheostomy management
  - appropriate stimulation and ongoing assessment of behavioural responses, albeit at low level
  - support for families.
- > If the nursing home does not have its own therapy team arrangements should be put in place by the CCG to provide a funded maintenance therapy programme through visits from the local community rehabilitation team or an alternative spot-purchased arrangement.
- > Long-term placement should take account of the needs of the family and ease of access for visiting – especially in circumstances where the patient responds best to family members and appears to gain positive life experience from family visits.

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### 3.13 Supporting families

E1/2

- > Families should be supported to be actively engaged in the care programme if they so wish, and be provided with tasks / activities that they can undertake with the patient, such as gentle massage / stretching, stimulating activities etc.
- > Families of patients with PDOC should be offered counselling and support at a stage when they are ready to receive this. Families are often not ready to engage with this support in the early stages, so the offer may need to be repeated.

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### 3.14 Review and monitoring

E1/2  
RA

- > There should be a nominated consultant in neurorehabilitation or neurology responsible for overseeing the review process. All patients in PDOC should remain under surveillance at least until they are diagnosed as being in permanent VS/MCS.
- > Patients in continuing or chronic VS or MCS should remain under active surveillance by a specialist PDOC service, and should be reviewed at least annually to provide specialist advice and to monitor for any significant change in the level of responsiveness or clinical condition.
- > Reviews should be conducted under the supervision of a specialist PDOC assessor, usually working on an outreach basis in conjunction with the local clinical team.
  - At a minimum, this should include application of the CRS-R (+/- the WHIM) and data should be entered on the National PDOC Registry, when this is developed.
- > Annual review should include a consideration and discussion of best interests. Appropriate ceiling of treatment arrangements should be discussed and agreed at each annual review.
- > Once a patient is diagnosed as being in permanent VS/MCS this should be confirmed and registered by an Expert PDOC Physician.
- > Thereafter it is good practice to update the register annually, eg though a follow-up telephone interview.

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### 3.15 Poor prognosis for recovery – permanent VS or MCS

E1/2

- > Once a patient is diagnosed by an Expert PDOC Physician as being in permanent VS or MCS, the CCG and treating team should meet with the family (and/or Welfare LPA if there is one) to appraise them of the diagnosis and consider the various options for further care and treatment.
  - > Formal discussion should take place about the patient's best interests in respect of continued active and life-sustaining treatment and (if not already in place) an agreed ceiling of treatment should be drawn up.
-

- > Treating teams and commissioners should not simply continue treatment because it is the easiest option.
    - Family members must be given ongoing opportunities to discuss withdrawal of life-sustaining treatment, including the practical, legal and emotional aspects.
    - It is the duty of the individual with overall responsibility for the patient's care to raise the issue, rather than waiting for family members to do so.
  
  - > If a decision is made to continue treatment, the CCG, treating team and family will agree: a) where this will be managed; and b) how it will be funded.
  
  - > These arrangements will be reviewed at least annually.
-

## Section 4

# The ethical and legal framework for decision-making

### 4.1 Introduction

All patients who possess mental capacity to make decisions about their treatment have the right to express their own choices, including the freedom to refuse treatments. By contrast, patients in PDOC lack the mental capacity to make decisions about their own care and treatments – and few people have recorded their wishes (formally or informally) in any form of advance decision or statement so these may not be known directly by those responsible for their care. This raises the following questions:

- > How do we decide what people want when they cannot tell us?
- > How do we assess what is in their best interests?
- > Who is responsible for making these decisions?

Joint guidance published by the BMA and the RCP<sup>4</sup> sets out detailed advice about *best interests* decision-making decisions to start, stop, continue or withdraw CANH in patients who lack mental capacity due to any condition. However, best practice in decision-making applies not only to serious or life-sustaining treatments, but to each and every intervention offered by clinicians to a patient who lacks mental capacity.

These guidelines focus on the broader range of treatments, but specifically for patients in PDOC.

- > This section sets out the ethical and legal framework for decision-making.
- > [Section 5](#) provides more specific advice about the different treatments and practical advice for implementation of the framework for patients in PDOC.

### 4.2 Ethical considerations – the subjective challenges

A detailed exploration of the complex ethical issues involved in this context is beyond the scope of this document. Ethics concerns itself with how we treat people, both individually and in general.

In simple terms, four operational principles underlie the day-to-day practice of the doctor. These are the responsibility to:

- > preserve life, restore health and relieve suffering
- > avoid medically unjustifiable harm
- > respect and account for the patient's right to autonomy

- > manage the patient's needs in relation to external factors, which may include the needs of others and fair distribution of resources.

However, these principles may conflict with one another and are often inadequate to deal with complex situations such as those posed by PDOC.

Where decisions are difficult, the *process* of decision-making is important. When formulating a certain treatment strategy for a patient who is unable to make the decision him/herself, the clinical team must balance and weigh the benefits and harms, not only from the medical perspective, but also in the wider social and personal context of the individual concerned, so far as it can be known.

It is important to remember that avoiding harm may include stopping or withdrawing treatment – or not starting the treatment in the first place. **Just because a treatment or intervention *can* be given, does not mean that it *should*.**

### Futile medical treatments

Modern medicine has provided us with a wide range of treatment options, many of which are very effective, although they can be harmful as well. In the context of PDOC, the profound brain injury is often the key factor that limits their effectiveness. The benefits of treatment enjoyed by the normal population are often not realised in this patient group, and the potential harms can sometimes be even greater.

A 'futile' treatment has been defined as one that, even though it may have a physiological effect, does not benefit the patient as a whole.<sup>120</sup> All treatments can cause harm; if a treatment offers no benefit, then all it can do is harm. Providing futile treatments also can carry significant dis-benefits to others or to society as a whole. While all patients, including those in PDOC, have a right to equitable care, clinicians have a responsibility to use the available resources wisely.

A clinician may decide that a given treatment would be futile or clinically inappropriate within the particular context of a patient's presentation, in which case they are under no obligation to offer it, and such decisions are made routinely as part of everyday clinical practice.

In legal terms, however, the concept of futility has created some debate.<sup>121</sup> The English courts have made clear that clinicians must be careful not to make value judgments about the condition that a patient might be restored to. If a patient is dying from a terminal illness, then a treatment could not be considered futile merely because it would not be able to reverse the course of the illness, so long as it was able to restore the patient to a condition that they themselves would find acceptable. Similarly, a treatment could not be considered overly burdensome simply because most patients would find the side effects unacceptable, if that particular patient *would* have been willing to accept them.

### Treating the patient with PDOC as a person – what might it be like to be in VS or MCS?

Self-awareness is one central element of human existence, but its existence in another person can never be known objectively – only inferred. Families often ask what it is like to be in VS or MCS, and whether the patient is in pain. A number of authors have addressed this question.<sup>122–</sup>  
124

### The example of pain

Pain is common in patients with other severe neurological disabilities and is likely also to be a problem in patients with PDOC. Possible sources of physical pain include:

- > **neurological** – damage to the central pain processing pathways, which may also cause hypersensitivity, allodynia etc
- > **musculoskeletal** – spasticity (typically experienced as cramps), joint malalignment and heterotopic calcification
- > **dental** – damaged teeth, abscesses and/or dental caries
- > **skin** – pressure areas, with or without actual pressure sores / wounds
- > **visceral** – bladder, bowels etc.

Patients in VS are traditionally believed to lack *any* ability to experience the environment, internal or external, but complete certainty that primal sensations are absent is impossible to know.<sup>124</sup>

Patients in MCS, on the other hand, are likely to experience both pain and other emotional responses<sup>125, 126</sup> in some form, but may not exhibit the behaviours that are usually seen in neurologically intact people with pain or distress.

There is a growing literature on perception of pain in PDOC, with evidence gathered from clinical studies, as well as neuroimaging and physiological research. In the main, neuroimaging studies, using fMRI, PET, multichannel EEG and laser-evoked potentials, suggest that the perception of pain increases with the level of consciousness.<sup>127</sup>

The majority of studies using these techniques suggest that pain-related brain activation patterns of patients in MCS more closely resemble those of healthy subjects.<sup>94, 122</sup> Some studies have shown that personalised painful stimuli evoke more evidence of pain perception than standardised nociceptive stimuli<sup>128</sup> and also possible emotional response and processing in some patients with MCS.<sup>129</sup>

While not provable, these findings offer plausible empirical reasons to suggest that living in MCS with some level of awareness could, in some circumstances, be a worse experience than living in VS with no awareness. Nevertheless, brain activation in response to noxious stimuli has also been observed in some patients who are behaviourally in VS,<sup>127</sup> so it is not safe to assume that even VS patients are pain free.

Clinicians are therefore urged to pay careful attention to the prevention, management and monitoring of pain and discomfort for patients with PDOC.<sup>130</sup> For example, the identification of a painful condition (such as a dental abscess or ingrowing toenail) should lead not only to the prescription of analgesia, but to treatment for the underlying problem. However, pain symptoms that accompany neurological disability (as described above) will not always be avoidable.<sup>124</sup>

Careful observation of pain-related behaviours (grimacing, moaning, groaning etc) provides the mainstay of monitoring and the presence of these features should be assumed to indicate discomfort rather than just reflex or spontaneous movement or behaviour, at least until there is clear evidence to the contrary.

In addition, clinicians should be aware of the social and emotional needs of patients – particularly those in MCS.<sup>126</sup> All of these factors should also be borne in mind when weighing up the balance of benefits and harms to inform *best interests* decisions relating to treatments that are given to prolong life.

### Decisions about life-sustaining treatments in PDOC

In catastrophically brain-injured patients, life-sustaining interventions are initiated in the hope that they will recover consciousness and a quality of life they would consider worthwhile, but there are reasons to be concerned about people who achieve only very limited recovery. While decision-making starts from the strong presumption that it will be in the patient's best interests to prolong life, this presumption can be rebutted if it becomes clear that they would not want to receive continued life-sustaining treatment in the circumstances that have arisen.<sup>4, 131</sup>

Life-sustaining treatment may encompass a number of interventions (which may include pre-existing treatments) such as:

- > **preventative measures**, eg thrombo-prophylaxis, statins, screening or immunisation programmes etc
- > **treatment for an acute event**, eg resuscitation in the event of cardiorespiratory arrest (CPR), escalation to intensive care, surgical intervention, the use of antibiotics in the case of a life-threatening infection
- > **longer-term treatments**, eg tracheostomy / assisted ventilation, renal dialysis and insulin for diabetes, steroid replacement therapy
- > **CANH**, which encompasses hydration and feeding both via the intravenous route and through nasogastric, gastrostomy or jejunostomy tubes.

As with any treatment on offer to patients who lack the capacity to decide for themselves, all of these interventions should be given only if they are judged to be in the patient's best interests, and the decision should be considered separately for each intervention whenever it is given or offered. This is important as a wrong decision could risk either life-sustaining treatment being withdrawn too soon (thus depriving the patient of an opportunity to live a life they would value), or of it being continued too long and so forcing the individual to continue a life they would not have wanted.<sup>4</sup>

In each situation, the doctor or healthcare professional's first task is to decide whether the life-sustaining treatment in question is, in fact, on offer. It may not be for a number of reasons:

- > Some treatments may be clinically futile in the sense of not being able to achieve their physiological aim.
- > Some treatments cannot be provided for technical reasons: for example, it might not be physically possible to reinsert a feeding tube for a person receiving CANH.
- > Some treatments are covered by specific policies: eg a hospital's policy that antibiotics cannot be used in certain situations because of the risk of bacterial resistance, or a particular drug does not meet national commissioning criteria.
- > There may be some other reason why the treatment is not clinically indicated in the specific circumstances of the patient's case.

If the treatment is not on offer – on one of the grounds set out above – the treating doctor cannot be required by the MCA 2005 to provide it.<sup>132</sup> The clinician would have to justify their decision not to offer it, but this is not a matter to be considered by reference to the MCA.

If the treatment *is* on offer, then (in the absence of a valid and applicable Advance Decision to Refuse Treatment) the normal *best interests* decision-making process will apply. The decision-maker is the clinician with overall responsibility for the patient's care, unless the patient has appointed a Welfare LPA with the relevant powers. The decision maker should consult the medical team responsible for the patient's care, the patient's family and friends, and anyone else who might be able to contribute an understanding of what the patient would have wanted. Some of these decisions can be made at the time they are needed, but others may need to be considered in advance.

Decisions not to attempt cardiopulmonary resuscitation (DNACPR) or to withdraw CANH are particularly emotive for a number of reasons and have historically been singled out for consideration by the courts. The relevant background is discussed below.

### 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR)

CPR has been singled out because:

- > it requires immediate action and so planning in advance from a very early stage in the care pathway
- > it has the potential to cause significant harm
- > despite the fact that attempts at CPR fail in most people, the public perceive it as universally life-saving and an entitlement by default
- > DNACPR decisions are sometimes misinterpreted as a decision for no active treatment.

### Success rates of attempted CPR

The GMC guidance for treatment and care towards the end of life<sup>133</sup> noted the general low success rate and the burdens and risks of CPR, including harmful side effects (eg rib fracture, damage to internal organs); adverse clinical outcomes such as hypoxic brain damage; and the fact that, if unsuccessful, the patient dies in an undignified and traumatic manner.

Even in the general population, CPR procedures carry a high risk of anoxic brain damage.<sup>134</sup>

- > At best only 15–20% of patients survive to discharge following an 'in-hospital cardiac arrest'<sup>135, 136</sup> and only 3–7% return to their previous level of functional capacity.<sup>134</sup>
- > Survival rates and outcomes are significantly poorer for out-of-hospital cardiac arrests<sup>137</sup> with only 5–6% surviving to discharge.
- > Quality of life among survivors is better for those who required only short resuscitation procedures (<2 minutes).<sup>138</sup>

The GMC guidance further noted that, in cases in which CPR might be successful in restoring cardiac output, it might still not be seen as clinically appropriate because of the likely clinical outcomes. When considering whether to attempt CPR, the clinical team should consider the likelihood of success, the benefits, burdens and risks of treatment that the patient may need if they do survive.

### DNACPR decisions and discussion with families

The decision of whether or not to attempt CPR requires careful consideration and, by definition, needs to be made ahead of the time when it might actually be required. If the decision has been made not to attempt CPR, the responsible clinician signs a 'DNACPR form' to communicate this decision to others involved in the patient's care. This, in effect, instructs the staff caring for the patient at the time not to initiate CPR or to call out the cardiac arrest team. The consultant/team is responsible for reviewing the instruction at appropriate regular intervals to confirm that the decision is still appropriate.

The 2010 GMC guidance emphasised that DNACPR forms should only be issued after discussion with the patient or their family.<sup>133</sup> This principle has been further emphasised in the recent court cases of Tracey<sup>139</sup> and Winspear.<sup>140</sup> The conclusion of both the above judgments was that doctors have a duty to discuss DNACPR decisions with the patient (or with their family if they lack capacity) if only to inform them of the decision.

- > A decision to delay or avoid communication of a decision to a patient must be based on that communication being likely to cause the patient 'physical or psychological harm'.
- > A decision to delay communication of a decision to the family / close circle of a patient without capacity must be based on that communication being either 'not practicable or not appropriate' in the circumstances.

It was acknowledged that many patients and/or their families may find involvement in this discussion distressing, but this is not reason enough to deny them the opportunity to express their wishes or to seek a second opinion.

The current joint guidance published by the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing, 2016,<sup>141</sup> provides the following advice:

'Even when CPR has no realistic prospect of success, there must be a presumption in favour of explaining the need and basis for a DNACPR decision to a patient, or to those close to a patient who lacks capacity. It is not necessary to obtain the consent of a patient or of those close to a patient to a decision not to attempt CPR that has no realistic prospect of success. The patient and those close to the patient do not have a right to demand treatment that is clinically inappropriate and healthcare professionals have no obligation to offer or deliver such treatment.'

Senior NHS clinicians have raised concerns about the practicality of implementing this advice within the melee of a 24-hour NHS service stretched well beyond its reasonable limits.<sup>142</sup> It was noted that either DNACPR forms would continue to be signed without the requisite discussion or (more likely in view of the career-threatening consequences for junior staff) the default would be to resuscitate with all of its unwanted consequences.

An NCEPOD enquiry in 2012<sup>143</sup> highlighted that many patients were undergoing inappropriate resuscitation attempts, because DNACPR orders were not completed in a timely manner, to the detriment of patient care. Shifting the focus from specific decisions about CPR, to making personalised plans on broader emergency care and treatment choices, may help to tackle some of the difficulties clinicians face with DNACPR decision-making and communication.<sup>144</sup>

The Resuscitation Council has since launched a UK-wide initiative (the ReSPECT process) to complement the process of advance care planning by drawing up personalised recommendations for a person's clinical care in a future emergency in which they are unable to make or express choices.<sup>141</sup> A similar approach can be used for patients in PDOC who have already lost capacity.

### Clinically assisted nutrition and hydration

Decisions about withdrawing CANH are also emotive for a number of reasons:

- > Because nutrition and hydration in any form are still considered by some to be a staple requirement and basic duty of care, rather than a medical treatment. The law, however, makes a clear distinction between oral feeding and clinically delivered food and liquid.<sup>145</sup>

The term 'CANH' was introduced by the GMC guidance in 2010<sup>133</sup> to emphasise that clinical procedures are part and parcel of nutrition and hydration.

- > For some people – both families and healthcare professionals – nutrition and hydration carry a special symbolic value associated with caring, and some ethical/religious frameworks may suggest that they should never be withdrawn.
- > Because death will inevitably follow within a few days or weeks of withdrawal – although this is equally true of other long-term interventions such as assisted ventilation, dialysis or insulin so in reality there are no reasons to single out CANH.

### Cause and mode of death

There is continued ethical debate about withholding and withdrawing life-sustaining treatment for people with PDOC. The debate is rooted in three issues:

- > What is causing the patient's death – the event that caused the brain damage or the removal of treatment?
- > The value of life for patients who are conscious, but unable to experience beyond a basic level, and are not terminally ill in the conventional sense.<sup>146</sup>
- > Whether death by dehydration, hyperglycaemia or uraemia may cause suffering – especially in patients with MCS – and whether that suffering may be greater or lesser than death by other means, eg infection.

Ethically and legally, the catastrophe that led to the brain injury is the cause of the PDOC and subsequent death.

- > Any medical intervention that continues to be needed only because of that event would never have been required, but for the brain injury.
- > Life-sustaining treatments postpone a death that otherwise would have happened at, or soon after, the time of the brain injury. Treatments may have to be started early, when the outcome is uncertain, but that in retrospect would not have been started had the eventual outcome been known.
- > The consequence of withdrawal of treatment is independent of how long after the event it is removed. The death remains the outcome of the brain injury.
- > It is wrong to continue a treatment that has no benefit because all it can do is nothing or to cause harm. Withdrawal is justified by the duty to avoid harm once a life-sustaining treatment is deemed no longer to be of benefit. It does not have the motive of bringing about death.

The difficulty is that the longer a treatment is in place, the more it can feel 'normal'. Hence withdrawing a treatment that has been established for some time may seem like a new or separate cause of a death, and clinicians may feel as though they are actively terminating life, rather than simply desisting from intervention to postpone death happening. Staff should be reassured that they are not legally culpable, so long as the proper legal decision-making process has been followed. Indeed continuing to give a treatment that is not in the patient's best interests potentially constitutes an 'assault' or 'battery'.

While cases under dispute may ultimately involve reference to the Court of Protection, the large majority can be resolved at a local clinical level on the basis of *best interests* decision-making.

### 4.3 Legal background – evolving case law related to life-sustaining treatment (including CANH) in PDOC

Since the development of the diagnostic category of the ‘permanent vegetative state’ in the early 1970s,<sup>6</sup> legal systems across the world have grappled with the question of whether it is legal to withdraw life-sustaining treatment in the clear knowledge that the patient will subsequently die. Clinicians and healthcare providers fear criticism (or even conviction) for failing to provide medical intervention, even when there is strong evidence that the patient would not want to receive it. Some countries have introduced a process of obtaining a ‘declaratory relief’, or a legal statement that it would ‘not be unlawful’ to withdraw treatment, thus protecting those responsible for the patient’s care from prosecution after the event. In other countries this is a clinical judgment.

The Human Rights Act 1998 means that doctors must be aware of how human rights will impact on their decision-making. The courts have confirmed that decisions to withdraw CANH are compliant with human rights law if they are made appropriately.<sup>147,148</sup>

In England, decisions regarding most life-sustaining treatments have remained in the hands of the medical profession, with the exception of CANH for which the case law has evolved over the course of the last 25 years. Appendix 4 of the BMA/RCP guidance on CANH for adults who lack capacity<sup>4</sup> sets out a detailed exposition of this development, from which some of the key milestones are set out in the next section. Some key points for clinicians to bear in mind are summarised in Box 4.1.

#### Key milestones in the case law related to CANH in PDOC

The first case to come before the English court seeking declaratory relief for withdrawal of CANH was that of *Airedale NHS Trust v Bland in 1993*,<sup>145</sup> concerning a young man who had been in VS for 4 years. The final judgment from the House of Lords established that CANH was a medical treatment and could be withdrawn on the basis that a treatment with no therapeutic benefit was ‘futile’. However, it recommended that, until a body of expertise and practice had been built up, decisions about withdrawing CANH from patients in VS should be brought before the court.

During the decade that followed, a number of further applications for declaratory relief were granted, generally on the grounds of futility of further treatment for patients in VS. However, introduction of the Mental Capacity Act 2005<sup>149</sup> led to a change in emphasis by requiring that any treatment for an adult who lacks capacity must be given on the basis of their best interests, taking into account their likely wishes. It introduced a framework for weighing up best interests on the balance of benefits and harms.

The first court application for CANH withdrawal from a patient in a diagnosed MCS was the case of *W v M 2011*.<sup>150</sup> The judge adopted a ‘balance-sheet’ approach, weighing up all of the factors for and against continued treatment. In this instance, declaratory relief was not granted, but the case established that it was reasonable (and indeed necessary) to bring such cases to court.

Practice Directions provide guidance to procedure for cases before the Court of Protection. From 2007 (when the Court of Protection came into being) until 2018, Practice Direction 9E governing ‘Serious medical treatments’ stated that ‘*decisions about the proposed withholding or*

*withdrawal of artificial nutrition and hydration from a patient in permanent vegetative state or minimally conscious state should be brought to the Court of Protection’.*

The case of *Aintree v James 2013*<sup>132</sup> involved an application to withhold a number of life-sustaining treatments (not CANH) from a patient in MCS. The Supreme Court judgment upheld a number of principles that are critical to medical decision-making in PDOC.

- > A patient cannot order a doctor to give a particular form of treatment (although they may refuse it) and the court’s position is no different.
- > However, any treatment which doctors do decide to give must be lawful. Generally it is the patient’s consent that makes invasive medical treatment lawful.
- > If a patient is unable to consent, it is lawful to give treatment that is in their best interests.
- > The fundamental question is whether it is in the patient’s best interests, and therefore lawful, to give the treatment – not whether it is lawful to withhold it.

The judgment emphasised further that best interests should be considered in the widest sense, not just medical but social and psychological.

- > Where a patient is suffering from an incurable illness, disease or disability, the prospects for success of a given treatment should be considered in respect of a return to a quality of life which the patient would regard as worthwhile.
- > The purpose of the *best interests* test is to consider matters from the patient’s point of view. That is not to say that their wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. But insofar as it is possible to ascertain the patient’s wishes, feelings, beliefs and values, it is those that should be taken into account in making the choice for them as an individual human being.

The case of *Briggs v Briggs 2016*<sup>131</sup> concerned a police officer who was in MCS 17 months after a severe brain injury sustained in a road traffic accident. His treating team considered that he might yet make further change with rehabilitation: the most realistic ‘best case’ scenario proposed by the treating clinician and independent expert was that he might emerge from his minimally conscious state, albeit without gaining capacity to make complex decisions, and (lacking insight into his condition) he could be ‘happy’. His wife and family disagreed: they believed that even the most optimistic prediction of recovery that he might achieve would not result in a quality of life that he himself would have valued. The judge concluded that, had Mr Briggs been able to exercise his right of self-determination, he would not have consented to further CANH treatment, and that his best interests were best promoted by the court not giving that consent on his behalf. CANH was consequently withdrawn.

During the 25 years or so following the Bland judgment, more than 50 applications were made to the court (first the High Court, and, after 2007, the Court of Protection). Provided clinicians agreed that the patient was in permanent VS, they had universally been allowed. However, the process for obtaining declaratory relief was time-consuming and expensive<sup>151</sup> as well as causing major distress for patients’ families<sup>152</sup> – and often also to healthcare professionals and carers.

Clinicians, lawyers and others<sup>153</sup> began to question whether Practice Direction 9E was still applicable – especially as it was not in itself legally binding and appeared to be in conflict with the binding effect of a valid and applicable Advance Decision to Refuse Treatment (ADRT). The Court of Protection Rules Committee withdrew Practice Direction 9E in December 2017, but

there remained some ambiguity, as the MCA Code of Practice still appeared to require a court application for patients in permanent VS.

The case of *An NHS Trust v Y 2018*<sup>148</sup> concerned a man in VS whose family and treating team were in full agreement that it was not in his best interests to continue CANH. His case was brought to the Supreme Court, not asking for a decision about Y's best interests, but asking if it was necessary to apply to the court for such a decision. After careful deliberation the Supreme Court judged that:

'If the provisions of the MCA 2005 are followed and the relevant guidance observed, and if there is agreement upon what is in the best interests of the patient, the patient may be treated in accordance with that agreement without application to the court.'

Following this judgment, the BMA and RCP drew up guidance<sup>4</sup> for *best interests* decision-making involving family and friends, proportionate external review and documentation guiding clinicians in responsible decision-making regarding decisions to start, re-start, continue or withhold CANH. That guidance, endorsed by the GMC and other bodies, including medical societies and allied healthcare professional societies bodies, has subsequently received judicial endorsement from the vice president of the Court of Protection.<sup>154</sup>

Box 4.1 summarises the key legal points for clinicians that are now enshrined in the law and are thus non-negotiable.

### Box 4.1 Key legal points for clinicians

- 1 Neither a patient nor their family, nor indeed the Court of Protection, can require a doctor to give a particular treatment. However, any treatment that doctors do decide to offer must only be given on the basis that it is in the patient's best interests, taking into account their likely wishes, insofar as these can be known.
- 2 It is the giving, not the withdrawing, of treatment that needs to be justified. Clinicians may not simply give treatment by default to avoid holding difficult conversations.
- 3 The critical question to consider of a patient in PDOC is no longer whether they may emerge from VS or MCS, but whether they will recover a quality of life that they themselves would value.

## 4.4 Legal framework for *best interests* decision-making

### The Mental Capacity Act 2005

The Mental Capacity Act 2005 (MCA)<sup>149</sup>‡ is a statute in force in England and Wales. It sets out a legal framework for determining mental capacity and making decisions on behalf of those 16 years old and over who lack the capacity to decide for themselves.

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‡Mental Capacity Act 2005: [www.legislation.gov.uk/ukpga/2005/9/contents](http://www.legislation.gov.uk/ukpga/2005/9/contents)

The equivalent legislation in Scotland is the Adults with Incapacity (Scotland) Act 2005. A Mental Capacity Act for Northern Ireland has been passed, but is not yet fully in force; currently decisions about medical treatment take place under the common law. These guidelines will not consider Scottish or Northern Irish legislation and readers are recommended to seek expert legal advice in those devolved parts of the UK about legal matters, but the general clinical principles will still apply.

Box 4.2 sets out the key features of the MCA. Section 1 of the MCA contains five statutory principles, which are designed to protect people who lack capacity to make particular decisions, but also to maximise their ability to make decisions, or to participate in the decision-making process, so far as they are able to do so. It also gives clear guidance on determining best interests and the processes that should be followed when making healthcare decisions on behalf of a patient. These should be applied separately to each decision that needs to be made.

The MCA also sets out the legal test of mental capacity and introduces a series of provisions to support *best interests* decision-making (including the appointment of an IMCA in some cases). It also makes provision to allow people to plan ahead for decisions regarding medical care and treatment, through ADRTs, or making a lasting power of attorney. The court may also appoint a Welfare Deputy after a person has lost the requisite mental capacity.

Disputes on matters that fall within the MCA are adjudicated by the Court of Protection, whose judges are empowered to make *best interests* decisions (in respect of a person who lacks capacity to make the relevant decision) under s.16, and to declare that a course of action by a health professional will be lawful (s.15).

The Official Solicitor, a family member or a specialist advocate can be appointed as a 'litigation friend' to represent a person lacking capacity in court. The Office of the Public Guardian, part of the Ministry of Justice, oversees the registration of powers of attorney and the conduct of deputies.

### Mental capacity in patients with PDOC

By definition, a person in PDOC will lack the mental capacity to make decisions regarding their welfare and/or treatment. Nevertheless, the lack of mental capacity should be formally documented in the patient records in accordance with the MCA test of capacity (see Box 4.2) along the following lines:

'X lacks the mental capacity to make decisions regarding his/her care and treatment because he/she lacks the ability to understand and retain information, to use or weigh it up in order to reach a decision, or to communicate a decision because of the severe brain injury they have sustained.'

In the absence of a valid and applicable ADRT, all decisions regarding care and treatment must therefore be made for patients with PDOC on the basis of their best interests. When determining best interests the decision-maker must take account of the views of anyone engaged in caring for the person or interested in his welfare and the reasonably ascertainable past wishes of the patient.

### Box 4.2 Key features of the Mental Capacity Act (MCA) 2005

Section 1 of the MCA contains five statutory principles designed to protect people who lack capacity to make decisions:

- 1 A person must be assumed to have capacity unless it is established that he/she lacks capacity.
- 2 A person is not to be treated as unable to make a decision unless all practicable steps to help him/her to do so have been taken without success.
- 3 A person is not to be treated as unable to make a decision merely because he/she makes an unwise decision.
- 4 An act done, or decision made, for or on behalf of a person who lacks capacity must be on the basis of a valid and applicable advance decision or must be done, or made, in his/her best interests.
- 5 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.

The MCA also:

- > makes it a criminal offence to wilfully neglect someone who lacks capacity (s44)
- > makes provision for people to plan ahead for a time when they may need support (s24)
- > confirms the status of Advance Decisions to Refuse Treatment (s24)
- > introduces an IMCA service to provide help for people who have no intimate support network (s35)
- > provides for the ability to create an LPA which allows people aged 18 or above (s9(2)(c)) to make appropriate arrangements for family members or trusted friends to be authorised to make decisions on their behalf. This can be with respect not only to property and financial affairs, but also to health and welfare matters through the appointment of a health and Welfare LPA (s9)
- > provides for the court to appoint a Personal Welfare Deputy (s16/17).

#### Lack of mental capacity

Capacity is specific to the decision to be made at the time it is made.

The MCA provides that a person lacks capacity to make a decision if:

(1) they cannot:

- > understand information relevant to the decision OR
- > retain that information OR
- > use or weigh that information as part of the process of making the decision OR
- > communicate the decision (by any means)

And

(2) their inability to do so is because of an impairment or disturbance in the functioning in the person's mind or brain.

### The position of 16/17 year-olds

The MCA applies to those aged 16 and above. In law, decision-making in relation to a 16- or 17-year-old lacking capacity to consent to or refuse can be undertaken either by reference to the MCA 2005 or by reference to the Children Act 1989 and the operation of parental responsibility at common law.

The GDG considers that the model of *best interests* decision-making contained in the MCA 2005 is better calibrated to the nature of the decisions that the guidelines cover, and so these guidelines proceed on the basis that decision-making should be undertaken under the MCA 2005.

On this model, the patient's parents (if they have parental responsibility) are not giving or refusing consent on their behalf; rather they are people to be consulted under s.4(7) MCA 2005.

## 4.5 Provisions within the MCA 2005 to support decision-making for patients who lack capacity

### Advance Decision Refusing Treatment

An adult (of 18 years and over) who has capacity may draw up an ADRT as a written refusal of treatments that they do not want to have in certain situations, in the event that they should lose the capacity for making those decisions for themselves.

A signed written ADRT that is valid and applicable to the clinical situation is legally binding on clinicians to follow. In this situation there is no need for a *best interests* discussion as the patient has already made their decision, which must be respected.

- > As with contemporaneous decisions, when adult patients with capacity make an ADRT, this does not have to be what others perceive to be a wise decision. The fact that others may not agree with the decision made does not mean that it can be overruled.
- > Even if the person now appears content, or even happy, with their quality of life, this does not mean that their ADRT is invalid.
- > Where there is genuine doubt about the capacity of the patient at the time to make the ADRT, or about its validity or applicability, legal advice should be sought and, if necessary, an application made to the Court of Protection.

Clinical teams should ask whether an ADRT is in place, and if so should request a copy to determine its validity and applicability to the situation at hand – they should not rely upon a second-hand report of it.<sup>154</sup>

If, for one reason or another, it does not meet the criteria to be legally binding, the ADRT must still be considered as a written statement of the person's values, wishes, feelings and beliefs which should carry weight in making a *best interests* assessment.

A suggested template for an ADRT is offered in electronic annex 4c ([www.rcplondon.ac.uk/pdoc](http://www.rcplondon.ac.uk/pdoc)), which includes treatment refusal options relating to life-sustaining treatment in the event of loss of mental capacity due to profound brain injury.

### Health and Welfare Lasting Power of Attorney

Sections 9–11 of the MCA 2005 make provision for LPA arrangements, and lay out the rules of appointment and restrictions to the role of a ‘Health and Welfare LPA’ donee (also commonly referred to as a ‘Welfare LPA’<sup>§</sup> or ‘Welfare Attorney’).

A person who has capacity may appoint one or more people as their Welfare LPA(s) to make decisions about health and welfare on their behalf when the person him/herself no longer has capacity. An LPA must have been registered with the Office of the Public Guardian (OPG) to take effect.

If more than one person is appointed, the LPA may specify whether they are to act:

- > ‘jointly’ (together) or
- > ‘jointly and severally’ (all or any one of them may make a decision) or
- > ‘jointly’ in respect of some matters and ‘severally’ in respect of others.

Where this is not specified, the LPA is to be assumed to appoint them to act jointly. The LPA(s) have a duty to decide always on the basis of the patient’s best interests.

The Welfare LPA’s authority is restricted to the extent that:

- > it cannot override an ADRT that is valid and applicable
- > it does extend to giving or refusing consent to medical examination or treatment
- > it *may* authorise the giving or refusing of consent to life-sustaining treatment, but only if the LPA document contains express provision to that effect
- > it may be restricted by other specific instructions within the terms of appointment.

Where the patient has a Welfare LPA, the treating team should ask to see a copy of the LPA document in order to confirm that this has been registered and to understand the terms of the authority and which individuals have authority for what decisions.

- > If the patient has a registered LPA that includes life-sustaining treatment, then (unless there is also a valid and applicable ADRT covering the same treatments) the power to consent to, or refuse, CANH and other life-sustaining treatment rests with the Welfare LPA, and clinicians should respect their decisions.
- > As with patients who have capacity however, Welfare LPAs do not have the power to insist on treatments that the healthcare team deems not to be clinically indicated.

Welfare LPAs must follow the principles of the MCA when making decisions and must act in the patient’s best interests (MCA Code of Practice 7.18–7.20).<sup>±155</sup> This will involve them carrying out a *best interests* assessment and consulting with carers, family members and others interested in the patient’s welfare. The clinical team will need to provide support, and cooperate with them in *best interests* discussions, to provide the information to enable them to fulfil this role.

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<sup>§</sup> Technically within the MCA, the term ‘LPA’ refers to the document that is drawn up to confer decision-making authority, rather than the donee themselves. However, in clinical settings the term ‘Welfare LPA’ is a widely understood and used shorthand term for the ‘donee of the health and Welfare LPA’, and is the sense in which it is used here.

<sup>±</sup> The MCA Code of Practice is currently under review, a new version being expected in Spring 2020, so this and any other paragraph references to the current Code of Practice will likely be out of date by then.

In the (thankfully rare) event that a Welfare LPA becomes ‘frozen’ and feels unable to face making a decision, there should not be paralysis – responsibility reverts back to the normal decision-making process under s5 of the MCA 2005. However, this should not be used to rush Welfare LPAs unreasonably into decisions for which they do not yet feel they have sufficient information.

If the clinical team has proper grounds to doubt that the Welfare LPA is acting in the patient’s best interests, they should seek to resolve the issue through discussion with the individual. If disagreement or doubt persists about whether the Welfare LPA is acting in the best interests of the patient, the Court of Protection should be asked to decide.

### Court-appointed Welfare Deputy

Under Section 16 of the MCA,<sup>149</sup> a Welfare Deputy may be appointed by the Court of Protection to make treatment decisions in respect of which a patient lacks capacity (s.19).

- > The extent of the Deputy’s powers will be delineated by the court on appointment.
- > Their appointment may relate to just one single treatment decision or to a more general power that covers a wide range of treatment and welfare issues.
- > A Welfare Deputy must always act in the patient’s best interests (s.20(6)).
- > A Deputy may never refuse consent to the carrying out or continuation of life-sustaining treatment (s.20(5)).

If a Welfare Deputy has been appointed to make treatment decisions on behalf of a person who lacks capacity, then it is the Deputy (rather than the healthcare professional) who makes the treatment decision, so long as it complies with the terms of their appointment.<sup>156</sup> The treating team should ask to see a copy of any court order that appoints the Welfare Deputy, in order to confirm and understand the scope of the Deputy’s authority. The Deputy’s powers extend to deciding whether the treatment(s) considered by the healthcare professionals to be an option should be given or not. The Deputy does not decide what the options are. As above, a Deputy cannot refuse life-sustaining treatment on behalf of the person.

### Independent Mental Capacity Advocate

If the patient has no family or other person able to represent their views or, for whatever reason, it is not considered appropriate to consult those who are close to the patient, an IMCA must be instructed.<sup>4</sup>

IMCAs are statutory advocates, which means that their involvement is required for certain decisions, in particular ‘serious medical treatment’ decisions, which would include decisions about life-sustaining treatment. An IMCA must be instructed where a patient is:

- > aged 16 years or over **and**
- > lacks capacity to make the specific treatment or accommodation decision **and**
- > there is nobody ‘appropriate to consult’ about the decision, other than those professionally involved in providing care and treatment to them.

IMCAs are independent of the NHS and local authority and are there to support the person when a *best interests* decision is being made on their behalf. They should be consulted about decisions and should be invited to contribute to *best interests* assessments, but do not have the power to consent to, or refuse, CANH.<sup>4</sup>

Advocates normally help people to express their views and wishes, secure their rights, access information and to be involved in decisions that are being made. Patients in PDOC are unable to be supported to express their views, but the IMCA still has a crucial role to play – which may include:

- > helping to collect and represent the person's prior expressed values and beliefs
- > ascertaining proposed courses of action
- > gathering the views of professionals and paid workers providing care or treatment and of anybody else who can give information about the wishes and feelings, beliefs or values of the person
- > accessing any other information they think will be necessary
- > considering whether getting another medical opinion would help the person who lacks capacity.

The IMCA then prepares a report, which must be taken into consideration in the determination of the patient's best interests.

### 4.6 Process to establish 'best interests'

Best interests are *not* restricted purely to medical considerations, nor do they necessarily mean the prolongation of life. This section sets out the process to establish best interests, which will necessarily need to be calibrated to the seriousness of the decision at hand.

The MCA and its code of practice emphasise:

- > that a broad range of matters are taken into account when deciding on a patient's best interests, including their known views on medical treatments, the acceptance of risk etc
- > the need to follow a proper process, and to document the process and the grounds for the decisions made
- > that being a family member does not, of itself, impart a right to make any treatment decision on behalf of an adult lacking capacity (save those formally appointed as a Welfare LPA or Deputy, who can then make healthcare decisions in prescribed circumstances).

Section 4 of the MCA 2005 lays out practical guidance and a checklist of points to consider when determining best interests. The decision-maker must be familiar with this checklist and know that determining a person's best interests is not simply a 'clinical decision'. Instead it considers a range of factors, including taking into account the patient's prior expressed values and beliefs – ie what the patient would have wanted for themselves, such as what treatments they would have consented to, or refused. This is where consultation with family and others who might provide pertinent information is essential. The MCA is a legal requirement and everyone's responsibility.

- > Every clinician is responsible for ensuring that any treatment they give to a person who lacks capacity is clinically appropriate and in their best interests.
- > Decisions to start, continue or stop life-sustaining treatments should be made by experienced clinicians working with the family/close friends, and supported by an independent second opinion if required (see Section 4.7.2).
- > Managers of organisations that provide care for patients (including NHS trusts, independent healthcare providers and nursing/care homes) must have processes in place to ensure that *best interests* decision-making is conducted in a timely manner and that

treatments are not simply given by default through lack of proper consideration and discussion.

- > Service commissioners (including NHSE/I and CCGs) must also ensure that the services they commission have these systems in place.

We recognise however that many organisations are not yet managing this well – either in the context of PDOC or for other patients who lack mental capacity. Although the framework presented here is focused on patients in PDOC, we hope that clinicians will also find it useful in other areas of clinical practice.

Box 4.3 summarises the key steps that the decision-maker must take when determining best interests.

In addition, as the MCA code of practice (para 5.41) states:

‘The person may have held strong views in the past which could have a bearing on the decision now to be made. All reasonable efforts must be made to find whether the person has expressed views in the past that will shape the decision to be made. This could have been through verbal communication, writing, behaviour or habits or recorded in any other way...’

It is important to manage *best interests* discussions to ensure that such information is fully ascertained, and fully incorporated into decision-making.

### Box 4.3 Key steps the decision-maker must take when determining best interests

*s4(6): S/he must consider, so far as is reasonably ascertainable –*

- (a) the person’s past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
- (b) the beliefs and values that would be likely to influence his decision if he had capacity, and
- (c) the other factors that he would be likely to consider if he were able to do so.

*s4(7): S/he must take into account, if it is practicable and appropriate to consult them, the views of*

- 
- (a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,
- (b) anyone engaged in caring for the person or interested in his welfare,
- (c) any donee of a lasting power of attorney granted by the person, and
- (d) any Deputy appointed for the person by the court,

*as to what would be in the person’s best interests and, in particular, as to the matters mentioned in subsection 4.6.*

For significant decisions, such as those to provide or withdraw life-sustaining treatment, decisions should be made and agreed by the whole of the treating team and those close to the patient and interested in their welfare.

- > Nevertheless, it should be established clearly, at all times, who has formal decision-making responsibility and this information should be shared with those close to the patient.

## Section 4 The ethical and legal framework for decision-making

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- > Seeking clarity about who the decision-maker is at an early stage ensures that life-sustaining treatment is provided, or withdrawn, as appropriate for the individual patient and is not simply continued, 'by default', because nobody sees it as their responsibility to carry out a *best interests* assessment.

*Best interests* decision-making is not a one-off process. Decisions may change over time, either as the patient's condition changes, as their prognosis becomes clearer,<sup>157</sup> or as family members reconsider what the patient would have wanted in changing circumstances.<sup>158</sup> It is therefore essential to re-visit decisions whenever relevant – but at least at each formal review.

In the BMA/RCP guidelines:<sup>4</sup>

- > Appendix 1 sets out some detailed practical guidance on how to conduct *best interests* decision-making in relation to CANH
- > Appendix 2 provides a checklist to record that the guidance has been followed.

Readers are referred to these useful resources, but as these RCP guidelines cover a wider range of life-sustaining treatments than just CANH, more general advice in *best interests* decision-making for patients in PDOC is set out in the next section (Key roles in decision making) and in [Section 5](#), with a *best interests* checklist in [Annex 4a](#).

### Key roles in decision-making

#### The role of the healthcare team

The healthcare team has a responsibility to act at all times in the best interests of a person who lacks capacity.

When a person no longer has the mental capacity to participate in decision-making, then the healthcare team can and should make healthcare decisions in accordance with the patient's best interests unless:

- > there is a valid and applicable ADRT in place that covers the specific situation
- > there is a Welfare LPA or court-appointed Welfare Deputy whose power of authority covers the decision in question.

The clinical team must check as soon as possible whether any of these are in place. They should ask to see the relevant documentation in order to understand the extent of any Welfare LPA or Deputy's decision-making power. Only in their absence (or where the Welfare LPA cannot face making the decision) does the treating clinician become the decision-maker – and then they have a duty to consult with the rest of the clinical team and with family members in order to inform their *best interests* decisions.

#### The role of the family and close friends

Although family members must be given the opportunity to contribute to decision-making regarding care and treatment, it is important to emphasise that, unless a family member has a relevant LPA or Deputyship, the responsible senior clinician has ultimate responsibility for healthcare decision-making based on judgment of what is in the patient's best interests. Such decisions must take account of what the patient would want if they could express a view. Having prior knowledge of the patient's prior character, beliefs, and what their wishes might be about treatment and care decisions, family members and close friends play a critical role to inform *best interests* decisions.

### *Who should be included in decision-making?*

Although it is standard clinical practice in most healthcare settings to identify just one individual as ‘**next of kin**’, there is no such legal concept. The MCA does not privilege any one relative’s views above another, but requires that there is consultation with and account taken of the views of ‘*anyone engaged in caring for the person or interested in his welfare*’ (s.4(7)).

Normal clinical procedure is for all communication between the family and the treating team to be channelled through the named ‘next of kin’, which has advantages in consistency and economies of time. While this individual still has a key role as the primary recipient of information, the frame of communication needs to be widened for *best interests* decisions, in order for the treating team to obtain a holistic picture of the patient’s character and preferences

Decision-making under the MCA 2005 is not defined by reference to ‘family’ members but to anyone who has a sufficiently close relationship with the patient to be ‘engaged in caring for the person or interested in his/her welfare’. It should include anyone whom the patient him/herself might wish to be involved in discussions about their care and treatment and, as such, has a legitimate interest that permits disclosure of clinical information as a part of providing support and *best interests* decision-making. As noted in Section 1, therefore, the term ‘*family*’ in this guidance is not restricted to legal or genetic relationships, but is used in this inclusive sense.

However, the MCA 2005 applies to each and every treatment decision, whether major or minor.

- > While the same basic principles apply to all treatment decisions, on a practical level the frame of discussion and consultation with family and friends must inevitably be wider for serious decisions (such as those relating to life-sustaining treatments) than for simple everyday care and treatment.
- > The MCA and much of the literature surrounding *best interests* decision-making tends to focus on serious medical treatments and to emphasise the need for a wide frame of discussion, whereas most people would consider it an invasion of their privacy to have detailed discussions about their intimate care needs (for example bowel and bladder care) shared widely with people whom they know only on a social level.
- > Clinicians must therefore find the correct balance between maintaining patient confidentiality and safe processes for decision-making in relation to more serious medical treatments.<sup>159</sup> The breadth of people to be consulted will vary for the decision at hand and a proportionate approach is required.
- > The person responsible for making the decision should ultimately decide how wide this consultation should be, but the decision of who to consult must not be influenced by a desire to achieve agreement on a particular course of action.

For the most significant decisions (such as those regarding life-sustaining treatments) it is important to ensure that attempts are made to identify all relevant people to be consulted about whether treatment would be in the patient’s best interests. Those consulted usually include family members and could also include friends, colleagues etc who have known the patient well and may be aware of their views and values. In some cases, a neighbour or close friend may have been more involved in the patient’s day-to-day life and have a clearer view of the patient’s wishes than family members, and so it is important to look beyond the immediate family to gain as much information as possible to feed into the decision-making process.<sup>4</sup>

Where there is disagreement between family members about what the patient would want, it is important for the treating team to document the various views and to record why a decision

was considered to be in the person's best interests. This is especially important if the decision goes against the views of somebody who has been consulted during the decision-making process (Code of practice 5.51–52).

### *Where there is no-one appropriate to consult with*

Where family and/or friends are considered 'not appropriate to consult with', then an IMCA must be appointed instead.

- > Family and friends should be deemed 'appropriate to consult' unless there are reasons to dispute this. It is not acceptable for them to be judged 'not appropriate to consult' simply on the basis that they are not in agreement with the proposed *best interests* decision or because there is some conflict between family or friends and the decision-maker.
- > The responsible body (NHS or local authority) should give the reasons for this and the rationale for involving an IMCA should also be given to the family.

(Electronic Annex 4b at [www.rcplondon.ac.uk/pdoc](http://www.rcplondon.ac.uk/pdoc) provides information about the role of family and friends in serious medical decision-making for people with VS or MCS).

### A summary of key roles in decision-making

It is important to be clear about terminology and the legal status of the different types of people that might be responsible for making decisions or whom the decision-maker might consult. A failure to distinguish clearly between these roles could leave a clinician in danger of treating without consent, or not giving treatment that is in the patients' best interests. It could exclude people from being consulted who should have been. It can also leave family members feeling responsible for decisions that are, in fact, not for them to enact. Table 4.1 summarises the different non-clinical people who can, and should, be involved in decisions.

## 4.7 Proportionate external scrutiny of decisions about life-sustaining treatments, including CANH

Clinical professions and NHS bodies are required to ensure that decisions about patients are made and documented with due diligence, for the protection and reassurance of all parties involved. A robust process is required to replace external scrutiny by the court to guard against the possibility either of allowing an avoidable death in a patient who might have recovered a quality of life that they would value, or of keeping them alive against their will in a condition that they themselves would not want.

The BMA/RCP guidance<sup>4</sup> sets out a framework for documentation and external scrutiny of decisions to withdraw CANH in patients who lack capacity to decide for themselves, including those in PDOC. The level of scrutiny should be proportionate to the consequences of the decision in each case. The consequences of the decision relate to:

- > the prognosis (both in terms of the level of any anticipated change in the level of awareness and the expected survival time)
- > the certainty with which these can be predicted
- > the impact on the individual of delaying the decision and/or of making the wrong decision.

This framework is summarised in the next section. Although the details may vary somewhat with the treatment decision at hand, it also forms a useful basis for consideration of other long-term life-sustaining treatments.

### Assessment and evaluation of the level of awareness and best interests

The first critical step is to gain a proper understanding of the patient’s level of awareness of themselves and their environment, and also their likely positive and negative experiences (eg pleasure, pain discomfort etc). As helpfully set out by Mr Justice Cobb in the case of *PL v Sutton CCG and Anor 2017*,<sup>160</sup> essential questions to consider are set out in Box 4.4.

**Table 4.1 Key terms for (non-clinical) people who might be involved in decision-making**

Term	Legal status for <i>best interests</i> decisions under the Mental Capacity Act 2005
<b>‘Next of kin’</b>	There is no such legal concept or status, but the ‘next of kin’ is usually a relative or close friend that has been nominated by the patient (often sometime in the past), through whom communication between the treating team and family is normally channelled.
<b>‘The family’</b>	No decision-making power (unless also appointed as Welfare LPA or Deputy – see below). But those close to the patient with a legitimate interest in their care and welfare, must be consulted in any <i>best interests</i> decisions in order to ascertain the patient’s prior values, feelings, wishes, beliefs etc. It is important not to assume who represents ‘the family’ and to think carefully about whom to consult with (see MCA Code of Practice).
<b>Decision-maker</b>	A person who is ultimately responsible for <i>best interests</i> decisions on behalf of a patient who lacks capacity. This is the Welfare LPA or Welfare Deputy if they exist, and their powers cover the issue in question. Otherwise it is the senior clinician with treating responsibility for the patient.
<b>Welfare LPA</b> (appointed <i>before</i> loss of capacity)	The decision-maker for the patient under the specific terms of their attorney appointment. The Welfare LPA may have been given the authority to give/refuse consent to life-sustaining treatment, but only if the LPA document contains express provision to that effect (MCA s.11(8)). If it does, then their consent to, or refusal of, life-sustaining treatment, is binding on the healthcare professionals.
<b>Court-appointed Welfare Deputy</b> (appointed <i>after</i> loss of capacity)	The proxy decision-maker for the patient under the specific terms of their court order. The extent of their powers depends upon the terms of the court order appointing them. If a Deputy has been appointed to make treatment decisions then once again that Deputy’s consent to, or withholding of consent to treatment, is binding on the healthcare professionals. However, <i>a Deputy may never refuse consent to life-sustaining treatment</i> (MCA s.20(5)).
<b>IMCA</b>	The IMCA cannot make decisions, but they advocate for the patient. An IMCA must be consulted in the absence of appropriate family/friends/Deputy/attorney, and they provide a report, which must be taken into account during <i>best interests</i> decision-making.

### Box 4.4 Essential questions to address when considering continuation/withdrawal of life-sustaining treatment

- > What is his/her current condition?
- > What is the quality of his/her life at present?
- > What is his/her awareness of the world around him/her?
- > Is there any, or any significant, enjoyment in his/her life?
- > Does he/she experience pain and/or distress, and if so, how is that managed?
- > What is his/her prognosis, if treatment were to be continued? Is there any real prospect of recovery of any functions or improvements to a quality of life that he/she would value?
- > What is the prognosis if treatment were to be discontinued? What would the palliative care package include?

Informed *best interests* decision-making requires a shared understanding of the likely prognosis in terms of both recovery of consciousness and life expectancy.

- > Although this is difficult to predict with accuracy, the clinician will need to estimate the worst- and best-case scenarios for return of consciousness and of functional independence / autonomy.
- > The prediction of life expectancy is never exact, but they also need to give a general estimation of the length of time that the patient would be likely to live for (eg in terms of days, weeks, months, or possibly years).
- > Finally, the family and treating team need to agree the level of uncertainty about the extent of recovery and whether the patient him/herself would value their quality of life in that condition over being allowed to pass away.

### Establishment of the level of awareness

Many patients in PDOC are medically stable and may otherwise be expected to live for a number of years. Some may have the potential to regain consciousness (particularly in the early weeks and months), but this becomes progressively unlikely as time goes on, as noted in [Section 1](#).

The perceived importance of obtaining a precise and definitive diagnosis has reduced over time, as it is increasingly recognised, by clinicians and the courts, that drawing a firm distinction between VS and MCS is often artificial and unnecessary. From a legal perspective, the diagnosis of VS or MCS (permanent or otherwise) is no longer critical to decisions about life-sustaining treatment, as the only important question is whether the patient will recover a quality of life that they would value.

Nonetheless, it is useful to estimate a person's actual level of awareness for two reasons.

- > It is important to know whether they have any awareness of themselves and/or their environment, because this may affect the quality of their experiences – both positive and negative.
- > Additionally, the evidence demonstrates a link between the level of responsiveness and the potential for recovering consciousness – the most important predictor being the trajectory of change, rather a diagnosis of VS or MCS *per se*.

For this reason, expert PDOC assessment in accordance with the guidance set out in [Section 2](#) of these guidelines is required to provide a detailed evaluation of their level of awareness of themselves or their environment, and to record any trajectory towards future recovery or deterioration.

### Informed *best interests* decision-making

In the absence of a valid and applicable ADRT, documented *best interests* decision-making meetings must be conducted with relevant family members and friends to establish what the patient's own likely wishes would be. Even where a Welfare LPA is the decision-maker, they must still act in the patient's best interests and will require information and support from the clinical team to do so. In order to be able to discuss what the patient may have wanted in different circumstances, family members must first be provided with the clinicians' best estimate of the worst- and best-case scenarios for return of independence, autonomy and life expectancy as described above. These scenarios should be included in the record of the *best interests* meeting, so that any external review process can determine the basis on which the decision(s) were made.

### External scrutiny

It is important to recognise that:

- > CANH may be clinically contraindicated in some circumstances – such as bowel obstruction, peritonitis or uncontrollable vomiting; or where re-establishment of a feeding tube is impossible or would be excessively invasive. In these situations, further attempts at feeding may be positively harmful.
- > It is also common practice to discontinue feeding (with the family's agreement) as part of a good end-of-life palliative care programme.
- > It is neither practical nor necessary to seek a second opinion if the patient is expected to die within hours or days.<sup>4</sup>

Otherwise, a second opinion forms a crucial part of the scrutiny that is essential when decisions are made by the clinical team not to provide or to stop CANH in patients who could go on living for some time.<sup>4</sup>

The BMA/RCP guidance is clear that in all cases where clinicians make a decision either not to start, or to withdraw, CANH in a patient who is 'not expected to die within hours or days', doctors should take all reasonable steps to obtain a second opinion from an independent senior clinician with the relevant expertise who is not part of the current treating team. The level of independence required depends on the circumstances and the consequences of the decision, and the guidance sets out recommendations for three clinical scenarios:

- > neurodegenerative conditions, such as Parkinson's or Huntington's disease or dementia
- > patients who have suffered a brain injury but have comorbidities or frailty which is likely to shorten their life expectancy
- > previously healthy patients who are in VS or MCS following a sudden onset brain injury.

The third group are the primary focus of this guidance, but even within this group there may be significant variation in life expectancy and certainty about prognosis due to a combination of other conditions, which may include age at injury and the type and severity of the brain injury, trajectory of change, time since injury, comorbidities and medical stability, which includes

tracheostomy, respiratory function etc. In addition, some patients in PDOC will have multiple health conditions or frailty and thus fall into group 2.

Accordingly, Table 4.2 sets out a framework for proportionate external scrutiny of decisions to withdraw CANH in patients with PDOC following sudden onset brain injury.

The exact form of scrutiny will depend on the patient's condition and prognosis and on the local availability of expertise.

- > If independent review is required, this should at least be by a senior medical consultant who is not directly involved with the patient's care, who has expertise in *best interests* decision-making and who approaches the question from a neutral stance. They must be able to make a decision either way.
- > Higher-level review is required for patients in PDOC who otherwise would be expected to live for a number of years. So far as is reasonably practical, the independent consultant should be from outside the treating organisation.
- > At least one consultant should be an expert in PDOC evaluation according to the criteria set out in [Annex 2b](#) of these guidelines – this may be the treating consultant or the second opinion.
- > The independent consultant should see the patient in person, other than in exceptional circumstances where this is not possible – in which case the reason for not seeing the patient should be documented.
- > For more nuanced decisions, where there is lesser certainty about prognosis for recovery, the Expert PDOC Physician may request an opinion from a second PDOC expert – usually in the form of a desktop review of the documentation from above.
- > Regardless of aetiology or prognosis, in patients for whom there is disagreement about best interests – either between the experts, or between the treating team and family – that cannot be resolved through discussion or mediation, a court application is required.

### Where there is a Welfare LPA authorised to make decisions regarding life-sustaining treatment

If the patient has had an assessment of their level of consciousness in accordance with the guidance in [Section 2](#), and the treating team has provided all the necessary information and support for the Welfare LPA to undertake the process of *best interests* decision-making under the MCA (including consultation and consideration of the patient's wishes, feelings, beliefs and values), the BMA/RCP/GMA guidelines<sup>4</sup> are clear that the Welfare LPA is *not* required to obtain a second opinion before deciding whether to consent to or refuse CANH on behalf of the patient. The fact that the patient has appointed them to make decisions on their behalf and the

## Prolonged disorders of consciousness

**Table 4.2 Framework for proportionate external scrutiny of CANH withdrawal in patients with PDOC following sudden onset brain injury**

Category	Condition and pathway	Level of scrutiny
<b>0</b>	Any patient with a valid applicable ADRT refusing CANH, or LPOA authorised to refuse life-sustaining treatments	Trust's clinical (and/or legal) team review ADRT/LPA documentation to confirm it is valid and applicable
<b>Patients in PDOC with a poor prognosis who are unlikely to live for more than a year</b>		
<b>1</b>	Patients for whom death is imminent (eg within hours or days) <ul style="list-style-type: none"> <li>&gt; or CANH contraindicated for clinical reasons</li> <li>&gt; or CANH is being withdrawn (with family's agreement) as part of an established end-of-life programme in a patient who is already dying</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Documented <i>best interests</i> decision-making, with the family and clinical team</li> <li>&gt; No external scrutiny required</li> </ul>
<b>2</b>	Patients in a condition (eg declining consciousness or other health conditions) that will inevitably result in death, not necessarily imminently but most probably less than 1 year.	<ul style="list-style-type: none"> <li>&gt; Documented <i>best interests</i> decision-making, with the family and clinical team</li> <li>&gt; Second consultant not directly involved with patient's care</li> </ul>
	<b>Family and treating team agree that continued CANH is not in the patient's best interests</b>	<p>(They should not be from the same department as the treating team, but may be from the same hospital. They should see the patient <i>in person</i>)</p> <ul style="list-style-type: none"> <li>&gt; Where a GP is the responsible decision-maker, the CCG should pay for a suitably qualified and experienced physician to provide the second opinion</li> </ul>
<b>Patients in PDOC with a stable or upward trajectory or who may live for a number of years</b>		
<b>Principles</b>	The level of scrutiny depends on the prognosis for recovery and the degree of uncertainty. These in turn depend on: <ul style="list-style-type: none"> <li>&gt; the age at injury and the type and severity of the brain injury</li> <li>&gt; the duration of PDOC</li> <li>&gt; any trajectory of change</li> </ul>	All should have: <ul style="list-style-type: none"> <li>&gt; documented <i>best interests</i> decision-making, with the family and clinical team</li> <li>&gt; expert assessment of PDOC (RCP guidelines)</li> <li>&gt; senior independent medical consultant (so far as is reasonably practical, they should be from outside the treating organisation)</li> <li>&gt; at least one of the consultants must be a registered PDOC expert according to the criteria set out in Annex 2b of these guidelines.</li> </ul>
<b>3</b>	<b>High degree of certainty about prognosis for recovery</b> Eg patients with very low-level disordered consciousness with a stable flat or downward trajectory, or long standing PDOC (eg permanent VS or MCS) for who there is a high level of certainty they will never regain consciousness.	
<b>4</b>	<b>Lesser certainty about prognosis for recovery, but agreement on best interests</b> Eg patients with a moderate/fluctuating level of response or shorter duration (continuing VS or MCS), but in who the family and treating team is in clear agreement that, even if they so did regain consciousness, they will never recover to a quality of life that they themselves would value.	<ul style="list-style-type: none"> <li>&gt; All of the above met and two senior medical consultants have already supported withdrawal</li> <li>&gt; The first PDOC expert may request a second independent consultant specialist in PDOC providing further confirmation – usually as a desktop review – to confirm that the documentation is sufficiently complete.</li> </ul>
<b>5</b>	<b>Patients for whom there is significant disagreement about best interests – either between the experts, or between the treating team and family</b>	<ul style="list-style-type: none"> <li>&gt; Documented <i>best interests</i> decision-making, with the family and clinical team</li> <li>&gt; Senior independent consultant with specialist experience of PDOC</li> <li>&gt; Application to the Court of Protection</li> </ul>

treating team has supported the decision-making process means that there is, in effect, the further check upon the robustness of the decision that was considered of importance by the Supreme Court in *An NHS trust v Y*.<sup>148</sup>

### Other life-sustaining treatments

Although other long-term life-sustaining treatments, such as dialysis, insulin, ventilatory support etc, have not been singled out by the courts as has CANH, a similar framework to that endorsed by the courts in relation to CANH may also be helpful when considering continuation/withdrawal of these treatments in patients with PDOC.

### When there have already been several consultants involved

PDOC is a highly specialist area. Increasingly as patients present earlier in the pathway, they may come into contact with more specialists over time. For example, it is not uncommon for a patient to have been seen in a tertiary level 1 PDOC assessment service and subsequently have had contact with their local district specialist rehabilitation physician and GP.

In the situation where the family and all of these doctors agree that further life-sustaining treatment is not in the patient's best interests (and all other requirements have been fulfilled) it is reasonable to ask if it is really necessary or appropriate to seek an opinion from yet another physician (who may be less experienced) purely on the basis they have not been previously involved in the patient's care. Under these circumstances, the GDG considered that this is not necessary, so long as the three doctors already involved are able to demonstrate that they have reached their opinion independently (for example they may have been involved at different stages, but not concurrently).

### The role of the second opinion

The second opinion senior clinician should:

- > have relevant clinical knowledge and experience;
- > have experience of *best interests* decision making;
- > not be directly involved with the patient's care;
- > be able to act independently, and;
- > be able, in principle, to make a decision either to continue treatment or not (ie does not have a conscientious objection to withdrawal of treatment).

Second opinion clinicians should carry out their own examination of the patient and consider and evaluate the medical records, the *best interests* process and its documentation. They should make their own judgment as to whether the decision in question is in the best interests of the patient, taking particular care to consider the issue from the patient's perspective. This will not require a full further *best interests* assessment to be carried out where the second opinion clinician is satisfied the original process has been sufficiently robust. Neither do they need to perform an independent evaluation of the level of consciousness, if this has already been done and documented in accordance with the recommendations in [Section 2](#).

Family members or those close to the patient should be informed about the second opinion review and have the opportunity to be present and to discuss the case with this person if they so wish. The second opinion clinician should seek a meeting or discussion if they consider it necessary to do so.

Where the second opinion clinician disagrees with the original decision, or has reservations or concerns about some aspects of it, this should be discussed with the original decision-maker to provide any additional information or to resolve the issue.

If the concerns or disagreement cannot be resolved through further discussion or the use of a medical mediator, legal advice should be sought and an application to the Court of Protection may be required.

### Documentation and recording

A pro forma is available on the BMA website to facilitate systematic documentation of decisions to withdraw CANH from patients in VS or MCS, in order to ensure that the above recommendations are met:

[www.bma.org.uk/advice/employment/ethics/mental-capacity/clinically-assisted-nutrition-and-hydration](http://www.bma.org.uk/advice/employment/ethics/mental-capacity/clinically-assisted-nutrition-and-hydration).

The organisation responsible for managing the patient and *best interests* decision-making should retain the detailed documentation and should be responsible for reviewing the quality of decision-making and care through their own internal clinical governance systems. These should also be subject to periodic external review from time to time, eg as part of CQC inspection as recommended in the BMA/RCP guidance.

Some organisations may wish to adapt these guidelines for local implementation within their own processes. This is acceptable so long as they do not deviate from or misinterpret the underlying legal principles. So long as these guidelines are followed it should not be necessary to introduce further steps prior to withdrawal such as independent review by a local Ethics Committee.

It is anticipated that the National PDOC Registry (when established) will have a section to record cause of death. Where there has been a decision to withdraw CANH or other life-sustaining treatments there will be a number of fields to record the level of external scrutiny (see [Section 6](#)). The registry should also include a list of medical consultants who fulfil the requirements for registration as a PDOC expert as set out in [Annex 2b](#).

## 4.8 Applications to the Court of Protection

If the above processes are followed correctly the large majority of decisions to start, stop, continue or withdraw life-sustaining treatments (including CANH) can be made by the treating team in conjunction with the family according to the principles in the MCA without any involvement of the court.

However the Supreme Court judgment also stated:<sup>148</sup>

‘If, at the end of the medical process, it is apparent that the way forward is finely balanced, or there is a difference of medical opinion, or a lack of agreement to a proposed course of action from those with an interest in the patient’s welfare, a court application can and should be made’...

‘...although application to court is not necessary in every case, there will undoubtedly be cases in which an application will be required (or desirable) because of the particular

circumstances that appertain, and there should be no reticence about involving the court in such cases.’

It is important to understand what this judgment means in practical terms. It does not require that *every* difficult decision needs to come to court. Clinicians face difficult decisions daily, many of which have potentially serious consequences. They have a range of tools and processes for making difficult decisions, and the Supreme Court in *An NHS trust vs Y* were primarily concerned with the robustness of the decision-making *process*.

Decisions related to the continuation or withdrawal of CANH may initially appear difficult because of a degree of clinical uncertainty which, in this context, will usually be about the patient’s level of awareness or their prognosis for recovery. Sometimes this uncertainty does not need to be completely resolved because there is strong evidence from those who knew the patient that even the best possible (realistic) level of recovery would not be acceptable to the person. Where necessary, it can often be addressed through more detailed expert evaluation or careful observation over a further (but limited) period of time to observe any trajectory of change.

For such decisions the GDG recommends that the treating team considers, in the first instance, either referral to a designated specialist PDOC centre for more detailed evaluation, or seeking further opinion from a senior PDOC expert with substantial experience of *best interests* decision-making. If the case does eventually require referral to the court this detailed information will, in any event, provide useful information for the court’s deliberations.

If ***at the end of the medical process*** of decision-making, the decision remains finely balanced, then this is the cue for considering whether an application to court is required. Going through the decision-making process will also identify whether there is a lack of agreement.

### Addressing disagreement

Where there is disagreement about what is in a patient’s best interests (whether within the clinical team, or between the team and patient’s close circle of family/friends) which cannot be resolved through discussion and/or mediation, the matter should be referred to the court. As the Supreme Court has made clear, this is an essential part of the protection of human rights.

### ‘Finely balanced’ decisions

Most situations where the decision remains finely balanced at the end of the process are, in reality, those where there is uncertainty about either capacity (not relevant in the context of PDOC) or best interests – for example:

- > where those close to the patient disagree about what she or he would have wanted
- > where, even without overt disagreement, some have residual doubts.
- > where the relationship between the patient’s close circle of family/friends and treating team is fragile and there is reason to believe that, while in agreement at the time of the decision, one or more may subsequently change their mind.

Other examples may be where the patient has never been able to express their wishes and feelings\*\* or where there is absolutely no information about their life before brain injury,

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\*\* Addressed in the context of CANH decisions by the BMA/RCP guidance at page 68.

despite the involvement of an IMCA. In reality, however, this group will be small as it is very rare not to be able to get some information about the individual's life story to guide the decision.

### Making applications

Any interested party can bring an application before the Court of Protection. Family members should not be placed in the position of having to make an application to the Court of Protection in relation to serious medical treatment decisions. In the case of disputes over capacity or best interests that cannot be resolved by mediation, the NHS commissioning body with overall responsibility for the patient has a duty of care to bring an application to the court as soon as practicable and to fund that application. Every effort should be made to ensure that applications are processed in a timely and efficient manner. Courts have criticised NHS trusts for long delays in making an application to the court where one is necessary.<sup>161</sup>

Box 4.5 presents a learning point for clinicians, commissioners and legal teams, based on a hybrid case scenario drawn from a combination of several real-life examples that illustrate less than ideal clinical practice and incorrect legal advice that is, unfortunately, not uncommon. The commentary explains what should have happened.

### Clinicians and conscientious objection

'Conscientious objection' is the claim that it would violate the individual's conscience to participate in a particular course of action, resulting in a loss of integrity or shame. A conscience may not, of course, be well informed, but the claim to conscience implies a certain seriousness of conviction or belief.<sup>162</sup>

The right to freedom of conscience in Article 9 of the European Convention on Human Rights was given effect by the Human Rights Act, 1998. Any practitioner is entitled to hold a moral viewpoint, but they are not entitled to impose that view on others.

Under the MCA 2005, health professionals may only provide treatment that is in the best interests of the individual patient. While CANH is formally established, and widely recognised, as a form of medical treatment, some health professionals set CANH apart from other forms of treatment and are not personally willing to withdraw it from patients who could otherwise go on living for some time. The BMA/RCP guidance 2018<sup>4</sup> provides the advice in relation to CANH, which is adapted in the following paragraphs to apply to conscientious objection to withdrawing other life-sustaining treatments.

There is no statutory right for health professionals to claim a conscientious objection to participating in the withdrawal of life-sustaining treatment (including CANH). Nevertheless, it is in nobody's interests for health professionals to be forced to participate in making or implementing such decisions (or to simply avoid making them) where there are others willing to take over that role.

**Box 4.5 Learning point for clinicians, commissioners and legal teams**

**Case scenario**

- > *The family of a man who has been in PDOC for 18 months approaches the GP saying that he would not value his current quality of life and would not wish to continue to have CANH.*
- > *The GP and the staff in the care home believe that they have a duty of care to continue to preserve the patient's life and are unwilling to discontinue CANH.*
- > *The GP contacts his defence organisation for advice and is told by their legal adviser that, as there is not full agreement between parties, the matter must be referred to the court. He is advised that if he/his partners wanted to withdraw treatment and the family disagreed, it would be they who approach the court. However, as it is the family who seek withdrawal, the next step would be for the family to seek legal advice with a view to bringing the matter to court.*

**Commentary**

The advice given in this example is incorrect for the following reasons:

- > It is the giving, not the withdrawing, of treatment that has to be justified. If the treatment is not in the patient's best interests, there is no duty of care to continue it – indeed continuing to give it would constitute an assault. Therefore, it is the treating organisation and the NHS commissioning body (in this case, the CCG) who are responsible for ensuring that the correct processes have been followed, and for bearing all the costs of doing so.
- > Family members should never have to initiate or pay for an application to the court in relation to serious medical treatment decisions.
- > The Supreme Court judgment did not require that every case in which there is disagreement should be referred to the court, but if there is still disagreement about best interests at the end of the medical process – which includes ensuring that the provisions of the MCA 2005 and the relevant professional guidance has been followed first.

**Before considering a court application in this case:**

- > The MCA 2005 requires properly documented *best interests* meetings conducted in an unbiased manner and always centred on the patient's own likely wishes and what he himself would regard as an acceptable quality of life – not on the beliefs or wishes of any other parties.
- > As *best interests* discussions require a shared understanding of both the patient's likely experience and their prognosis, there should be a formal assessment of his level of consciousness and evaluation by an Expert PDOC Physician.
- > The beliefs of the GP and care staff should be explored to determine the origin of their concerns.
  - If, for example, they arise from discomfort about withdrawing the care that they have been delivering for a long time, alternative arrangements for end-of-life palliative care may need to be made if CANH is withdrawn.
  - If they arise from conscientious objection and the staff members involved (or the care home) could not sanction a *best interests* decision to withdraw life-sustaining treatment, they should hand over the care of the patient to a clinician who could.
- > In the event of continued disagreement about the patient's best interests it is appropriate to consider whether this can be resolved through mediation before referring the matter to court.

Where disputes over best interests cannot be resolved by mediation, the NHS commissioning body with overall responsibility for the patient must bring an application to the court as soon as practicable and must fund that application. Submission of the documentation from the medical process should help to ensure timely and efficient processing of court applications.

The strongly held personal views of members of the healthcare team must not stand in the way of a decision being made that is in the best interests of the individual patient, whether that is to provide or to withdraw life-sustaining treatment. As with other circumstances, health professionals must provide information in an unbiased and honest way, admitting uncertainty where it arises. When providing this information, health professionals should take particular care to ensure that their personal views about the patient's quality of life – or about the nature of the treatment – do not influence the way in which clinical information is presented to those close to the patient or affect their attitude towards those, including family members, who do not share those views.<sup>163</sup>

Where health professionals have a conscientious objection to the withdrawal of CANH, they have a responsibility to recognise this as a potential conflict of interest when considering decisions about life-sustaining treatment; this should be declared prior to beginning discussions within the healthcare team or with those close to the patient. If individual clinicians could not sanction a *best interests* decision to withdraw life-sustaining treatment, they should hand over the care of the patient to a clinician who could. Where, however, a health professional does not disagree in principle with the withdrawal of life-sustaining treatment but believes, in a particular case, that it is not appropriate, this should lead to further discussion and, where appropriate, a further clinical opinion being sought.

A health professional who believes that life-sustaining treatment should never be provided in particular categories of patient, and could not agree to continuing to provide life-sustaining treatment under such circumstances, should also recognise that their views present a potential conflict of interest and transfer the patient's care to a colleague.

Provider organisations, including care homes, that carry religious or other convictions that would prevent them from making and implementing particular decisions about life-sustaining treatment should be open about that fact when a *best interests* decision is needed. All such organisations have a duty, however, to comply with the law, including ensuring that *best interests* assessments are carried out on a regular basis.<sup>157</sup> These assessments should specifically consider the question of whether life-sustaining treatment continues to be in the patient's best interests, including as part of the care plan review. Where necessary, they should make arrangements for these assessments to be carried out in, or by staff from, another establishment.

Some health professionals do not have a conscientious objection to withdrawal of life-sustaining treatment but are nonetheless anxious or uncomfortable about making such decisions. Continuing treatment 'by default', however, in order to avoid making these difficult decisions, is contrary to the interests of patients and health professionals' legal duties under the Mental Capacity Act, and could amount to assault or battery if the patient would in fact not wish to receive it. Following this good practice guidance, staff training and seeking support and advice from colleagues, may help to provide reassurance.

## Section 4 Ethical and legal framework for decision-making: Summary of recommendations

Recommendation	Grade
<p><b>4.1 Futile or clinically inappropriate medical treatments</b></p> <p>Clinicians should be aware that:</p> <ul style="list-style-type: none"> <li>&gt; if they decide that a given treatment would be clinically inappropriate within the particular context of a patient’s presentation, they are under no obligation to offer it, and this is not a matter to be considered with reference to the Mental Capacity Act</li> <li>&gt; however, when this decision may have serious consequences, it is good practice to inform the patient’s family of this decision</li> <li>&gt; in cases of dispute it is wise to seek a second opinion.</li> </ul>	<p><b>E1/2</b></p>
<p><b>4.2 Clinical obligations under the Mental Capacity Act 2005</b></p> <p>Clinicians must be aware of the MCA and its provisions for patients who lack capacity with respect to patients who lack capacity.</p>	<p><b>Legal requirement</b></p>
<p><b>4.3 Documentation of lack of capacity</b></p> <p>Assessment of mental capacity must be specific to the decision in hand at the time that it is made. By definition, however, patients in PDOC lack the mental capacity to make decisions regarding their care or treatment.</p> <p>The lack of mental capacity should be formally documented in the patient records in accordance with test of capacity contained in the MCA along the following lines:</p> <p>‘X lacks the mental capacity to makes decisions regarding his/her care and treatment because he/she lacks the ability to understand and retain information, to weigh it up in order to reach a decision, or to communicate a decision because of the severe brain injury they have sustained.’</p>	<p><b>E1/2</b></p>
<p><b>4.4 Decisions regarding treatment and care for patients in PDOC</b></p> <ul style="list-style-type: none"> <li>&gt; Unless the decision is already covered by a valid and applicable advance decision to refuse treatment (ADRT), all decisions should be undertaken on the basis of best interests, under the terms of the Mental Capacity Act 2005.</li> <li>&gt; Clinicians should be aware that:             <ul style="list-style-type: none"> <li>– Any treatment that they do decide to offer must only be given on the basis that it is in the patient’s best interests, taking into account their likely wishes, insofar as these can be known.</li> <li>– It is the giving, not the withdrawing of, treatment that needs to be justified.</li> </ul> </li> </ul>	<p><b>Legal requirement</b></p>

- They may not simply give treatment by default to avoid holding difficult conversations.

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#### 4.5 ADRT and Welfare LPA or Deputy

Legal  
requirement

The healthcare team should establish **as soon as possible** whether:

- > the patient has made a valid and applicable ADRT covering the clinical situation that has arisen; if so, it must be followed (MCA s.26), and no *best interests* decision is required
- > the patient has a Health and Welfare Lasting Power of Attorney ('Welfare LPA') or a court-appointed Welfare Deputy whose powers extend to cover the particular treatment decision in question; if so their decision must be respected (s.19(6) and s.9(1)(a)).

However, Welfare LPAs and deputies must act in the patient's best interests in consultation with others interested in the patient's welfare in accordance with the MCA. The clinical team will need to provide support and information to enable them to fulfil this role.

The treating team should ask to see documentation for any ADRT, LPA or Deputy in order to understand whether they cover the treatment decision in question.

- > If an ADRT does not meet the criteria to be legally binding in relation to the decision, it should nevertheless be considered in *best interests* decision-making.
- > If the Welfare LPA's or Deputy's powers do not extend to making this particular decision they must nevertheless be consulted about healthcare decision making and their views taken into account (s.4(7)).

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#### 4.6 Identifying 'family' and close friends

E1/2

- > The clinical team should identify those individuals who are close to the patient and whom the patient might wish to be involved in discussions about their care and treatment – and as such have a legitimate interest that permits disclosure of clinical information as a part of providing support and '*best interests*' decision-making.
- > Teams should be aware that these are not restricted to legal or genetic relationships but may include close friends and others who can provide information about their prior values, beliefs and wishes and so help to formulate *best interests* decisions.

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#### 4.7 Independent Mental Capacity Advocate (IMCA)

E1/2

When a patient does not have any close family or friends to represent and advocate their views then an IMCA must be appointed and consulted in respect of *best interests* involved.

Where family and/or friends are considered not 'appropriate to consult with' an IMCA must be appointed instead. The responsible body (NHS or local authority)

should give the reasons for this and the rationale for involving an IMCA should also be provided to the family.

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### 4.8 *Best interests decision-making*

Legal  
requirement

In the absence of a valid and applicable ADRT, or appointed Welfare LPA / Deputy, decisions regarding care and treatment should be made by the treating team on the basis of best interests, taking into account what is known about the patient's likely wishes.

Families, friends and others should be consulted as part of the decision-making process, but it should be made clear that they are being asked what the patient would have wanted under those circumstance, not for their own wishes.

The *best interests* checklist should be used to document the decisions required and ensure that the appropriate people are involved in the decision-making process.

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### 4.9 *Decisions regarding life-sustaining treatment including CANH (in the absence of a valid and applicable ADRT)* E1/2

When considering a *best interests* decision to withdraw life-sustaining treatment, the critical question to consider of a patient in PDOC is no longer whether they may emerge from VS or MCS, but whether they will recover a quality of life that they themselves would value.

- > The first essential step is to gain a proper understanding of the patient's level of awareness of themselves and their environment and their likely positive and negative experiences.
- > Patients should have an expert assessment (as set out in [Section 2](#)) to provide a detailed evaluation of their level of awareness and to record any trajectory towards future recovery or deterioration.
- > When making *best interests* decisions, the decision-maker should, as far as 'practicable and appropriate' consult with
  - anyone named by the person as someone to be consulted on such matters
  - anyone engaged in caring for the person or interested in his welfare
  - any Welfare LPA or Deputy.
- > The consultation will normally include family members, but may also include close friends and others who have the relevant information about the patient's prior values, feeling, wishes and beliefs that could help to inform the decision.
- > The scope and extent of this consultation will depend on the individual circumstances and should be proportionate to the consequences of the decision to be made. The decision of who to consult lies with the

decision-maker, but should not be influenced by a desire to achieve agreement on a particular course of action.

- > *Best interests* discussions should include all members of the treating healthcare team, especially those who have worked closely with the patient.
- > Those consulted should be provided with the clinicians' best estimate of the worst- and best-case scenarios for return of independence, autonomy and life expectancy, and these scenarios should be included in the record of the *best interests* meeting.
- > The following should be clearly understood:
  - Treatment decisions are the responsibility of the clinical team.
  - The family is not being asked to make decisions about treatment, but to provide information about the patient's prior wishes, feelings, values and beliefs in order for the decision-maker to formulate those decisions.
  - The focus is on what the patient him/herself would want, not what the family want for the patient, or would want for themselves in this situation.
- > Healthcare professionals need to be aware that those consulted may find it hard to separate their own views and preferences from those of the patient. Seeking views from a range of people and asking for examples or supporting evidence for the views expressed may help to ensure that decisions are focused on the patient.

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### 4.10 Second opinion for decisions to withdraw CANH

E1/2

Where a decision is made not to start, or to withdraw, CANH in a patient who is not otherwise expected to die within hours or days, doctors should take all reasonable steps to obtain a second opinion, which should be funded by the NHS commissioning body with overall responsibility for the patient.

The second opinion senior clinician should:

- > have relevant clinical knowledge and experience;
- > have experience of best interests decision-making;
- > not be directly involved with the patient's care; and
- > be able to act independently.

For a patient who has frailty or other health conditions and is expected to die within 1 year:

- > the second opinion may be from within the same organisation so long as they have not previously been involved in the patient's care.

For a patient in PDOC who is expected to live for a number of years:

- > so far as is reasonably practical, the independent consultant should be from outside the treating organisation, and

- > at least one consultant should be a registered PDOC expert according to the criteria set out in **Annex 2b** of these guidelines.

The second opinion physician should carry out their own examination of the patient and consider and evaluate the medical records, the *best interests* process and its documentation.

- > They should make their own judgement as to whether the decision in question is in the best interests of the patient, taking particular care to consider the issue from the patient's perspective.
- > This will not require a full further *best interests* assessment to be carried out where the second opinion clinician is satisfied the original process has been sufficiently robust.
- > They do not need to perform an independent evaluation of the level of consciousness, if this has already been done in accordance with the recommendations in **Section 2**.

Family members or those close to the patient should be informed about the second opinion review and have the opportunity to be present and to discuss the case with this person if they so wish.

Where the second opinion clinician disagrees with the original decision or has any concerns, this should be discussed with the original decision-maker to provide any additional information or to resolve the issue.

If the concerns cannot be resolved through further discussion or a medical mediator, legal advice should be sought and may require an application to the court.

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### 4.11 Applications to the court

E1/2

If the provisions of the MCA 2005, the Code of Practice and the relevant guidance have been observed, with respect to *best interests* decision-making, and if all parties (including family members, treating team and second opinion) are in agreement that it is not in the patient's best interests to continue CANH, then this can be withdrawn without application to the court.

An application is not required simply because the decision initially appears difficult. Clinicians should follow the decision-making process in this guidance to determine whether the decision is ultimately one that is finely balanced or one upon which agreement cannot be reached.

If the initial decision appears difficult because of uncertainty about the patient's level of awareness or their prognosis for recovery, making the balance of benefits and harms, it may be helpful to refer them to a designated specialist PDOC centre for more detailed evaluation, or to seek a further opinion from a senior PDOC expert with substantial experience of prognostication and *best interests* decision-making.

If, at the end of the clinical decision-making process, there is disagreement between any of the parties that cannot be resolved by discussion and/or

mediation, then the matter should be referred to the Court of Protection. Similarly, an application should be made if the decision is ultimately one that is finely balanced due to residual uncertainty about best interests.

Family members should not be in the position of having to make an application to the court in relation to serious medical treatment decisions.

- > If a court application is required, the NHS commissioning body with overall responsibility for the patient has a duty of care to bring an application to the court and to fund that application.
- > Every effort should be made to ensure that applications made as soon as practicable and are processed in a timely and efficient manner.

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### 4.12 Supporting clinicians to make appropriate *best interests* decisions

E1/2

Clinical staff should be aware that:

- > The catastrophe that led to the brain injury is the ultimate cause of the PDOC and subsequent death.
- > Life-sustaining treatments postpone a death that otherwise would have happened at, or soon after, the time of the brain injury.
- > The consequences of withdrawal of treatment, no matter how long after the event, should be regarded as due to the brain injury.
- > The decision to withdraw treatment is justified by the requirement to avoid harm once life-sustaining treatments are no longer judged to be a benefit, and not motivated by a desire to bring about death.

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### 4.13 Conscientious objection

E1/2

Health professionals should ensure that their personal views do not influence the way in which clinical information is presented or affect their attitude towards those, including family members, who do not share their views.

If the individual clinician could not sanction a *best interests* decision in one direction they should hand over the care of the patient to a clinician who can.

If an institution providing care for a patient being considered for withdrawal of life-sustaining treatment does not support or allow withdrawal, then they should state this publicly and inform the family and the commissioning organisation **before** admission. They must:

- > arrange for independent collection and collation of diagnostic data (if needed)
- > allow an independently run best interests meeting
- > facilitate transfer to another organisation if needed – either during the decision-making and legal process, or if a decision to allow withdrawal has been agreed.

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### 4.14 Staff training

E1/2

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Clinical teams are often reluctant to open discussions on best interests, particularly regarding life-sustaining treatment, because they lack the knowledge and practical experience of how to go about this. As this is a legal requirement:

- > Training on the law governing the Mental Capacity Act 2005 and the responsibilities of clinicians with respect to *best interests* decision-making should form a standard part of clinical training programmes for all staff who come into contact with patients who lack the mental capacity to make decisions for themselves.
  - > Clinicians who are likely to become lead decision-makers for patients with profound brain injury should be able to demonstrate training and competency in the practical conduct of *best interests* discussions and decision-making (see [Section 5a, Recommendation 5.1.14](#)).
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## Section 5a

# Practical decision-making regarding starting or continuing life-sustaining treatments, including clinically assisted nutrition and hydration

### 5.1 Background

In general, day-to-day care and treatments given to control symptoms or improve ease of care will be in the patient's best interests. All other significant treatments, especially those aimed at prolonging life, require careful consideration, particularly if it becomes apparent that the patient is unlikely to recover to a quality of life that they themselves would value.

Life-sustaining measures are often initiated in the acute stages of care in the hope that the patient will recover to a level that they would regard as providing a good quality of life. Even if these measures are started after a *best interests* discussion, it is important to review all decisions on a regular *and planned* basis because the longer a patient remains in PDOC, the less likely further recovery becomes. A *best interests* decision that is right for a patient at one point in time is not necessarily right for them months (or years) later.

As noted in [Section 4](#), the decision-making process needs to be tailored in proportion to the nature of the treatment decision in hand.<sup>159</sup> Serious medical treatments inevitably require a wider frame of discussion than simple everyday care issues.

Joint guidance published by the BMA and the RCP<sup>4</sup> sets out detailed advice about *best interests* decision-making decisions to start, stop, continue or withdraw CANH in patients who lack mental capacity due to any condition. These RCP guidelines focus specifically on patients in PDOC but cover a broader range of treatments.

- > Section 4 sets out the ethical and legal framework for decision-making.
- > This section provides more specific advice about the different treatments and practical advice for implementation of the framework, with particular focus on decisions about life-sustaining treatments.

### 5.2 The range of life-sustaining treatments

Life-sustaining treatments fall into two broad categories, as illustrated in Table 5.1. As part of clinical treatment planning it is appropriate to consider decisions about all of these interventions.

Table 5.1 Categories of life-sustaining treatment

Category	Examples
<b>Escalation of unplanned immediate or urgent interventions</b> for life-threatening events that may/may not arise	<ul style="list-style-type: none"> <li>&gt; ACPR in the event of cardiac/respiratory arrest</li> <li>&gt; Surgical or other invasive intervention (eg for an acute abdomen, hydrocephalus etc)</li> <li>&gt; Intensive / high-dependency care in the event of acute instability</li> <li>&gt; Antibiotics in the instance of life-threatening infection</li> </ul>
<b>Elective medical interventions</b> designed to sustain or prolong life	<ul style="list-style-type: none"> <li>&gt; Prophylactic treatments (antithrombotic or seizure prophylaxis, cardioprotective agents, implantable pacemakers /defibrillators)</li> <li>&gt; Other treatments, screening or preventative interventions that may have been started pre-injury (eg bowel or breast cancer screening, immunisation or treatments for unrelated conditions)</li> <li>&gt; Long-term treatments, such as dialysis, tracheostomy/assisted ventilation, insulin, steroid replacement therapy</li> <li>&gt; CANH</li> </ul>

ACPR = attempts at cardiopulmonary resuscitation; CANH = clinically assisted nutrition and hydration

### Immediate and urgent interventions

Patients in PDOC are often medically unstable and may become unwell suddenly and unpredictably. Some life-threatening conditions may require rapid ‘out-of-hours’ intervention by emergency teams who are unfamiliar with the patient, and so require advance treatment planning.

- > In the absence of a valid and applicable ADRT that covers the treatment in question, clinicians should firstly consider whether to offer the treatment.
- > The decision to offer invasive and potentially harmful treatment must be considered on each individual’s presentation and circumstances.

### Cardiopulmonary resuscitation

Although cardiac arrest is one of the least likely causes of sudden deterioration in this group of patients, decisions on attempted cardiopulmonary resuscitation (ACPR) have historically been singled out for consideration for the reasons described in Section 4. Contemporary guidance on ACPR is available from the Resuscitation Council: [www.resus.org.uk/dnacpr/](http://www.resus.org.uk/dnacpr/).

Despite public perception that it is universally life-saving and an entitlement by default, survival rates and favourable neurological outcomes from ACPR are rare even under optimal circumstances.<sup>136, 137</sup> For patients with very severe brain injury, even short periods of hypoxia are likely to lead to further brain damage and a worse clinical outcome. Therefore, ACPR is unlikely to be clinically appropriate in the large majority of patients in PDOC.

In certain circumstance, however, there may be some valid clinical reasons for ACPR:

- > Depending on the nature and extent of the brain injury, there may be genuine uncertainty about the prognosis for recovery in the first few weeks after injury.

- > In some settings, calling the cardiac arrest team may be the only way of getting rapid medical attention – for example in the event of simple reversible problem, such as a blocked tracheostomy, which could lead to cardiorespiratory arrest if not dealt with rapidly.

In these situations, it may be appropriate to offer a short attempt at CPR, but this should be recorded and accompanied by a clear direction with respect to the ceiling of treatment escalation, in order to guide on-call teams who are not familiar with the patient.

- > Such instructions should not be confused with ‘go slow’ or half-hearted attempts at CPR, which will never be appropriate and must not be endorsed.
- > They are specific instructions to assist the emergency medical team in providing effective and appropriate care for defined conditions, while avoiding excessive intervention that is clinically unjustified and more likely to result in harm than good.<sup>164</sup>

Whether or not the clinical team decides to offer CPR, this must be discussed with the patient’s family<sup>133</sup> – see [Section 4](#).

- > Inability to discuss DNACPR decisions with the family should not preclude the decision being made, but there should be a high threshold for withholding the information.<sup>141</sup>
- > It is equally important to communicate to the family if resuscitation is to be offered in order to check whether this is what the patient would have wanted under the circumstances.
- > Discussion should be normalised as far as possible within the context of a wider Treatment Escalation Plan (see ‘Section 5.4 Treatment escalation and ceiling of treatment plans’).

### Major surgery

Urgent surgical interventions may include neurosurgical procedures (eg decompression, shunt placement for hydrocephalus, etc) or other interventions (eg for acute abdomen, airway management, haemorrhage etc).

Patients in PDOC typically present a high risk for general anaesthetic due to a combination of impaired swallow, inability to protect their airway, poor respiratory excursion and loss of homeostatic reflexes. When weighing up the benefits and harms of surgical intervention, clinicians should consider carefully both the risks of surgery and the anaesthetic.

### Antibiotics

Many patients in PDOC have a prolonged stay in hospital. Autonomic dysregulation presents with pyrexia, sweating, tachycardia and tachypnoea which are often mistaken for signs of infection by the acute medical teams and treated without question with broad-spectrum antibiotics under the hospital’s ‘sepsis guidelines’. Such practice increasingly leads to colonisation with multi-resistant bacteria,<sup>165</sup> which compromises their future treatment for genuine sepsis. Even if infection is present, antibiotics may not be necessary. The majority of patients in PDOC have normal immune systems that are capable of combatting an infection that is not immediately life-threatening.

It is good practice, therefore, to avoid the use of broad-spectrum antibiotics unless clearly indicated by the patient’s condition. If the patient is not critically unwell, it is advisable to wait for the results of cultures and antimicrobial sensitivity – and, even then, clinical teams should

consider carefully whether treatment of infection is: a) necessary; and b) in the patient's best interests.

### 'MET' call / escalation to intensive or high-dependency care

Most hospitals now field a rapid-response medical emergency team (MET) to manage acutely sick patients out of hours. If the patient remains unstable after the initial intervention, they will typically be transferred to ITU/HDU. In the early stages post-injury when the outcome is uncertain, such a transfer is often appropriate, but later on this enhanced medical care may prove futile in terms of overall benefit to the patient in PDOC. Clinical teams should consider carefully whether a MET call and its subsequent implications are appropriate to the individual's condition and likely prognosis, and should review this decision on a regular basis.

### Emergency 'blue light' admission to hospital

For patients in the community, acute transfers to hospital typically involve a significant wait for assessment (with its attendant risk of pressure sores etc) and then admission to a busy ward where staff are not familiar with the complex neurological needs of PDOC patients. Emergency admission to hospital should be avoided where possible, especially where patients have little to gain from acute medical/surgical intervention. As the chances of making a meaningful recovery from catastrophic brain injury diminish, it may be appropriate to set a ceiling of home-based treatment only. This may still allow active management but may, for example, involve giving medications that can be administered in that setting via a PEG, but not more invasive treatments or intravenous medications.

### Longer-term medical treatments designed to sustain or prolong life

In addition to the more unpredictable treatment, patients in PDOC typically receive a number of longer-term medical interventions to prolong or sustain life. These may include treatments to protect against future illness, to compensate for organ dysfunction or to sustain nutrition and hydration. The decision to continue each of these should be reviewed on a regular basis.

### Prophylactic and preventative treatments

Patients in PDOC are typically given a variety of prophylactic and preventative treatments. These may include antithrombotic or seizure prophylaxis, cardioprotective agents, implantable devices (eg pacemakers, defibrillators etc) cancer screening, immunisation etc. While appropriate in the early stages post-injury, the usefulness and relevance of these needs to be kept under review to decide whether continuation is justified.

### Tracheostomy

A tracheostomy may be maintained for a number of different reasons:

- 1 to reduce the respiratory 'dead-space' and so facilitate breathing
- 2 to provide direct access for suction of excess secretions
- 3 to protect from aspiration of saliva (with cuff inflation)
- 4 to bypass upper airway obstruction (eg subglottic stenosis, arytenoid oedema)
- 5 to provide access for invasive ventilator support.

Generally speaking, airway management is considered a priority for treatment, but on the other hand, a long-term tracheostomy carries its own set of problems.

- > The tracheostomy tube needs to be changed every month, which is logistically challenging when people are no longer in hospital.

- > A tracheostomy forms an entry point for bacteria, increasing susceptibility to chest infections.
- > Over time, friction between the tube and tracheal wall can lead to granulation tissue and stenosis. Occasionally tracheostomy tubes have been known to erode through the tracheal wall into the adjacent major blood vessels causing catastrophic (and usually fatal) haemorrhage, which is very distressing for all concerned.
- > Tracheostomy care is a complex intervention that requires highly skilled nursing care. The presence of a tracheostomy will inevitably limit the range of options for nursing home placement and may result in patients being placed a long way from their home, so reducing the opportunity for regular contact with their families.
- > Importantly, for some patients in MCS-plus, a tracheostomy may impede any form of speech and deprive them of the limited opportunities that they do have for communication with friends and family.

With increasing pressure on hospitals for early discharge, patients in PDOC are often discharged to nursing home care with a tracheostomy still in place but no clear plan for review other than regular tube changes. Local teams are understandably cautious about tracheostomy weaning but experience suggests that a proportion of patients will recover the ability to protect their own airway over time, and for others the harms outweigh the benefits.

Patients with tracheostomies should therefore be kept under regular review by teams experienced in tracheostomy management to consider the reasons and justification for continued cannulation.

### Other longer-term treatments

Other pre-existing or longer-term treatments may include insulin for diabetes, dialysis for renal replacement, assisted ventilatory support (invasive or non-invasive) and CANH.

## 5.3 Responsibility for decision-making

As noted in [Section 4](#), if a clinician decides that a given treatment would be futile or clinically inappropriate within the particular clinical context of a patient's presentation, they are under no obligation to offer it,<sup>132</sup> and this is not a matter to be considered by reference to the MCA, although in cases of dispute it is wise to seek a second opinion.

If the treatment *is* on offer, the normal *best interests* decision-making process will apply as set out in the Mental Capacity Act 2005 and its guidance. It is essential to remember, however, that the burden of proof lies with the clinician to justify the *giving*, not *withdrawal*, of a treatment, and this should be the case with any treatment at any stage.

For each decision that is (or may be) required, it is important to establish who is responsible for decision-making. [Section 4](#) sets out the legal responsibilities for decision-making, but they are summarised again in [Box 5.1](#).

**Box 5.1 Key steps to establish the responsibility for decision-making about escalation plans**

**Step 1: Is there a valid and applicable ADRT that refuses the treatment in question?**

- a If there is, the patient has already made their choice and it must not be given, regardless of whether the clinician considers this to be a sensible decision.

**Step 2: (if no ADRT) is the treatment likely to be effective and clinically appropriate?**

- a If not, the clinical team is under no obligation to offer it, and this cannot be demanded by the patient's representatives and there is no need to hold a *best interests* meeting.
- There should, however, be a strong presumption in favour of explaining this to their family without delay even though it may cause distress.
  - If this explanation was not 'practical or appropriate' the reasons for this should be documented.
- b If there is disagreement that cannot be resolved after sensitive discussion, a second opinion should be obtained.

**Step 3: If the treatment is (or may be) on offer:**

- a **Where there is a Welfare LPA in place** and the terms of their appointment expressly cover decisions about life-sustaining treatment, then the Welfare LPA:
- can make a legally binding decision to accept or refuse the life-sustaining treatment for the patient at the time that it is offered
  - cannot make an advance decision on behalf of a patient, but they should be involved in *best interests* discussions about escalation planning.
- b **Where there is no Welfare LPA / Deputy in place:**
- The responsibility for determining whether or not treatments are in the patient's best interests lies with the lead clinician with clinical responsibility for the patient at the time. It is they who determine whether treatment should be started, continued or stopped.
  - Family / carers / next of kin do not have decision-making responsibilities or rights in this circumstance.
    - They should never be placed in a position such that they feel they are making a decision regarding life-sustaining treatment.
  - Discussion with the family should be focused on trying to ascertain the patient's own wishes, feelings, values and beliefs prior to incapacity, as part of determining their best interests.

**A court-appointed Welfare Deputy** cannot refuse life-sustaining treatment but should nevertheless be kept informed of decisions taken by the clinical team, and should be involved in 'discussions'.

The team should also consider whether an **IMCA** is needed to help represent the patient in any decision.

In the absence of a valid and applicable ADRT, Welfare LPA or Deputyship, decisions about care planning and end-of-life management are ultimately made by the responsible senior clinician on the basis of the patient's best interests in discussion with the family and members of the treating team. This holds some particular challenges, however, and this section provides some practical advice on how to approach these discussions.

### Acquiring information to inform *best interests* decisions – discussion with family and friends.

When determining a patient's best interests in respect of serious medical treatments, the decision-maker must take account of the views about the past wishes of the patient from 'anyone engaged in caring for the person or interested in his welfare'.<sup>149</sup>

As noted in [Section 4](#), a proportionate approach is required depending on the decision at hand, but the frame of consultation will necessarily be wider for important decisions (including those about life-sustaining treatments) than for decisions about everyday care and treatment.

Family members are often key here – but the people consulted are not confined to those genetic or legal ties to the patient. They can include close friends, colleagues, and anyone else who may have information relevant to what the patient him/herself might have wanted in this situation. It is important to manage *best interests* discussions to ensure that such information is fully ascertained, and fully incorporated into decision-making.

In the aftermath of catastrophic brain injury, however, initiating discussion with family/friends may be challenging for a number of reasons.

#### Challenges for clinicians:

- > Many health professionals find it difficult to deliver 'bad news' and have limited training and skills to handle expressions of distress when strong emotions and feelings are being expressed by family members.
- > Some perceive treatment withdrawal as a personal 'failure' and do not want to 'give up' on the patient.
- > Limited experience of a few cases may influence judgements and lead to over-optimistic assumptions about recovery and reluctance to 'give up hope' regardless of the patient's own, known attitude toward a major brain insult.
- > Some find it hard to take responsibility for decision-making about withholding or withdrawing life-sustaining treatments as they confuse this with causing death – especially when that death might follow rapidly.

#### Challenges for family/friends:

- > Especially in the early stages following brain injury, the patient's family may still be in considerable distress over the loss of the person they knew and loved, and may not yet have come to terms with the patient's poor prognosis for recovery.
- > They may have been given very little, or sometimes contradictory, information about prognosis. (For example, in spite of a specialist doctor giving a clear poor prognosis, families quite frequently report that other members of the team had given them reason to hope.)
- > They may interpret a decision not to offer CPR or other treatment escalation as an instruction for 'no active treatment' and feel that the medical team is 'giving up on' the patient.
- > Despite careful explanation about the scope of decisions and that the clinical team is responsible for them, some families still believe that they personally are being asked to make the decision to withdraw treatment, and they do not want the burden of responsibility or to feel implicated in the patient's death.

### Experience of family and friends

Some families report that they feel excluded from the decision-making process, while others report that staff put inappropriate pressure on them to offer opinions concerning life-changing decisions for which they lack knowledge.<sup>166</sup>

Families regularly report that clinical staff are ill-informed about the proper processes that should be followed in decision-making about life-sustaining treatment.<sup>152</sup> For those who feel strongly that a patient's prior expressed wishes to reject treatment should be respected, it can be deeply upsetting to come up against clinicians who dispute the possibility of withdrawal, cite conscientious objections or claim that withdrawing life-sustaining treatments in this situation is 'unethical', 'illegal' or 'tantamount to euthanasia'. It is very important that all staff working with PDOC patients have adequate training in the current law governing this area of care and in the practical conduct of *best interests* decision-making.

All families, regardless of their views on what the patient would want, may also feel distressed about the available options for end-of-life planning.<sup>119</sup> In all these scenarios, families require information and support.

Moreover, family attitudes may change over time. Having often been told in the early stages that the patient is likely to die, families may interpret their survival against the odds as evidence of the patient's will to live and a sign of future recovery,<sup>119, 167</sup> but with hindsight, efforts to save their loved one's life may be viewed with regret. One family member said: *'Would that they hadn't got to Charlie in time to resuscitate him – knowing now what I didn't know then'*.<sup>119</sup> Even those who fight for all active measures in the early months or years may change their minds about the appropriate course of action in the future.<sup>119</sup>

This underlines the importance of continued communication with the provision of information and support for families, and a willingness to listen to them over the course of the patient's continuing treatment. Some learning points for clinicians are summarised in Box 5.2. Further information for families is provided in [Annex 4b](#).

## 5.4 Treatment escalation and ceiling of treatment plans

Immediate and urgent interventions often require a rapid response from people who are less familiar with the patient.

- > Treatment escalation and end-of-life planning is normally considered as part of advance care planning – a discussion between an individual, their care providers, and often those close to them, about future care undertaken before the person loses capacity.<sup>169</sup> This allows a fuller discussion and maximises the opportunity to acquire relevant information.
- > Many of the same principles can and should be applied for people who lack capacity using the *best interests* process.

It is good practice for the treating team to consider ahead of time the most significant or likely clinical events which may occur, and how best to manage them, even though the patient cannot take part in the discussion.

**Box.5.2 Learning points for clinicians**

Clinicians must be aware of the following in relation to any information given:

- > some family members may have their own strong beliefs – religious, personal, philosophical – about healthcare decisions that may lead to distress and can influence the information that they do and do not disclose.
- > they may find it hard to separate their own wishes and beliefs from those of the patient.\*
- > some will feel personally responsible for any decision made, especially if the person dies or is left alive but in distress, leading to guilt.\*\*

Being clear about roles, rights and responsibilities and managing the relationships and communication between all concerned must therefore be a priority and subject to constant review. In the absence of an ADRT, Welfare LPA or Deputyship, it should be made clear that:

- > **Treatment decisions are the responsibility of the clinical team.**
- > **The family is not being asked to make decisions about treatment**, but to provide information about the patient's prior wishes, feelings, values and beliefs for the decision-maker to formulate those decisions.
- > **The focus is on what the patient him/herself would want**, not what the family want for the patient, nor what they would want for themselves in the patient's situation.

**A decision made in a person's best interests is not necessarily the same as the whole family being happy about a particular decision** (for example, a family cannot easily be expected to say that they 'want' or 'are happy' to allow death) but they may nevertheless believe the decision is consistent with what the person would want.

\*Kuehlmeier K *et al* 2012<sup>167</sup>; \*\* Crawford S *et al* 2005<sup>168</sup>

For reasons discussed in [Section 4](#), discussion relating to DNACPR can be especially emotive. However, the focus of attention on ACPR and DNACPR decisions has tended to detract from the consideration of other unplanned life-prolonging interventions in the acute/immediate post-acute setting that may also have specific implications for patients on PDOC. Rather than singling out ACPR as a special case, this should be discussed as part of an overall individualised Treatment Escalation Plan in line with the ReSPECT process.

Care planning and treatment decisions should be considered by the clinical team together with the family from an early stage in the pathway. This can be challenging at a time when families are still coming to terms with the effects of catastrophic brain injury. When discussing the various treatments, it is often helpful to start with the most likely scenarios (eg seizures, infections etc) and those for which interventions *are* likely to be offered. In the context of this general conversation, decisions not to offer CPR and/or other invasive treatments are less likely to be interpreted as a blanket withdrawal of care. Box 5.3 summarises some specific advice about communicating Treatment Escalation Plans.

**Box 5.3 Communicating decisions regarding treatment escalation (including ACPR)**

The discussion should include a clear explanation of the following:

- > That future care planning is a routine part of clinical decision-making that is considered for all patients who are unable to express their own wishes.
- > This includes plans for the most likely scenarios, eg infection, seizures and sudden cardiac arrest.

Good practice starts with discussion about the most common scenarios and actions (eg antibiotics for infection, prophylaxis for seizures etc) and progresses to the less likely events with the poorest outcome (eg ACPR and escalation to intensive / high-dependency care).

The clinician should explain:

- a why the intervention is unlikely to benefit the patient
- b what the likely outcome would be
- c that the decision whether or not to offer treatment lies with the treating team and not with the family.

That, except where one of them is a health and Welfare LPA with authority to make decisions regarding medical treatments, the family's only role in this respect is to indicate what they believe the patient would have wanted in this context.

**Planning the withdrawal of life-sustaining treatments**

While life-sustaining treatments may be started or continued on the proper initial premise that it is in the patient's best interests to prolong life, there is no requirement to continue them if it becomes clear that the patient him/herself would not want them. In some instances, it is reasonable to give limited trials of treatment, such as assisted ventilation, without incurring the need for a lengthy process of documentation and second opinions to end the trial.

However, as death will often follow their discontinuation within a matter of days or weeks, it is important both to ensure that the decision-making process is robust and to put in place an appropriate palliative care plan to control any anticipated symptoms and to manage end-of-life care appropriately.

Whenever it becomes clear that it is unlikely the patient will recover to a condition that they would regard as offering a reasonable quality of life, it is time to consider whether to start, continue or withdraw any life-sustaining treatment. Each of the treatments that are relevant to the individual should be considered separately and the reasons for each decision documented.

When considering withdrawal of CANH, clinicians should follow the procedures set out in [Section 4](#). Readers are also referred to the guidelines relating to CANH published jointly by the BMA and the RCP,<sup>4</sup> which offer guidance for all patients who lack the capacity to consent, including those in PDOC, and a useful practical toolkit.

Provided that all parties agree on what is in the person's best interest and good practice has been followed with respect to decision-making involving the family and treating team in accordance with the provisions set out in the MCA 2005, CANH can be withdrawn without the necessity to apply to the Court of Protection for endorsement of the decision.

Although they are not mandated for withdrawal of other life-sustaining treatments, the procedures and system for proportionate external review in [Section 4](#) also provide a useful framework for considering withdrawal of other long-term life-sustaining treatments (such as insulin for diabetes, dialysis for renal failure) where death may be expected to follow within a few days or weeks after they are stopped. Unless the patient is within hours or days of death, it is advisable to seek a second opinion from an independent consultant who has not previously been involved in the patient's care.

### Documentation of treatment decisions and escalation plans

Whatever decisions are made, they should be recorded in writing clearly and unambiguously. The documentation should be readily available to anyone involved in the patient's care, at the time when they become relevant.

At any point in time, each patient should have a clear treatment plan describing what treatments are or are not to be given. Patients in PDOC should have a written escalation plan that has been agreed by the multidisciplinary clinical team and discussed with the family. This should be placed in a prominent position in the patient's records (for example at the front of the notes alongside any DNACPR form) and reviewed at regular intervals and in the light of any change in the patient's condition or if additional information comes to light.

A pro forma for completing a Treatment Escalation Plan is given in electronic [Annex 5a](#).

Table 5.2 illustrates an exemplar Treatment Escalation Plan for patient X who was in VS following a hypoxic brain injury. His prophylactic medications and tracheostomy had been weaned without incident. A planned ceiling of escalation had been agreed with his family while decision-making regarding CANH withdrawal was in progress. For peace of mind the family had asked for a little more time to consider this, and a further *best interests* meeting was planned in 3 months.

### Ongoing escalation planning

Where a carefully drawn up Treatment Escalation Plan exists, it is unwise for it to be revoked as a matter of course on change of care setting. In particular, the factors that have led to a conclusion that ACPR would not be in the patient's best interests in the context of PDOC are unlikely to change over time, so once a decision has been made it is very unlikely to be revoked unless the patient emerges into consciousness. Repeated discussion with the family each time the patient moves to a different care setting may cause unnecessary distress. Therefore, DNACPR forms and other Treatment Escalation Plans should remain valid and applicable across all settings including acute care, nursing home and ambulance transport until an agreed review date or a change in condition.

Receiving hospitals and care homes should not simply rescind a pre-existing Treatment Escalation Plan without a further and properly documented *best interests* determination having been made. However, it is incumbent on the discharging team and the receiving team to review any Treatment Escalation Plan on transfer to ensure that the decisions are still applicable in the new setting.

Table 5.2 Exemplar Treatment Escalation Plan for patient X (as agreed with his family)

Treatments <i>not</i> to be given	Treatments that <i>may</i> be considered depending on the circumstances	Treatments that will be given/continued
<b>Treatment plan on admission for PDOC assessment programme, 3 months post-injury</b>		
<ul style="list-style-type: none"> <li>&gt; CPR</li> <li>&gt; Escalation to ITU/HDU</li> <li>&gt; Major surgery</li> </ul>	<ul style="list-style-type: none"> <li>&gt; IV/PEG antibiotics in the event of life-threatening infection</li> </ul>	<ul style="list-style-type: none"> <li>&gt; All supportive care</li> <li>&gt; Analgesia as required</li> <li>&gt; Antithrombotic prophylaxis</li> <li>&gt; Seizure prophylaxis</li> <li>&gt; Tracheostomy</li> <li>&gt; CANH</li> </ul>
<b>Treatment plan on discharge to a nursing home at 6 months post-injury</b>		
<ul style="list-style-type: none"> <li>&gt; CPR</li> <li>&gt; Escalation to ITU/HDU</li> <li>&gt; Major surgery</li> <li>&gt; Blue light transfer to hospital</li> <li>&gt; IV antibiotics</li> <li>&gt; Reinsertion of tracheostomy</li> </ul>	<ul style="list-style-type: none"> <li>&gt; PEG antibiotics if clinically indicated for symptoms only</li> </ul>	<ul style="list-style-type: none"> <li>&gt; All supportive care</li> <li>&gt; Analgesia as required</li> <li>&gt; CANH, pending further <i>best interests</i> decision-making with family in 3 month's time</li> </ul>

CANH = clinically assisted nutrition and hydration; CPR = cardiopulmonary resuscitation; HDU = high-dependency unit; ITU = intensive treatment unit; IV = intravenous; PEG = percutaneous endoscopic gastrostomy

A link between the proposed national clinical registry for patients with PDOC and electronic records relating to palliative and end-of-life care would be extremely helpful in this respect, for ensuring that any *best interests* decisions regarding ceiling of treatment are transmitted on to those healthcare systems that need to know this information within a very short space of time (eg 10–15 minutes) to aid appropriate decision-making. The national scheme 'Coordinate My Care' may also form a useful platform to transit this information to emergency services including ambulance teams and out-of-hours general practitioners:

[www.coordinatemycare.co.uk/mycmc/](http://www.coordinatemycare.co.uk/mycmc/).

### Practical arrangements for *best interests* decision-making involving life-sustaining treatments

Helpful guidance on the practical aspects of setting up, running and recording *best interests* decisions exists already<sup>4, 159</sup> and will not be repeated here

([www.bma.org.uk/advice/employment/ethics/mental-capacity/mental-capacity-toolkit](http://www.bma.org.uk/advice/employment/ethics/mental-capacity/mental-capacity-toolkit)).

However, some specific areas that typically cause difficulty are highlighted in the following subsections.

### Responsibility for decision-making

Every clinician is personally responsible for ensuring that any intervention they provide to a patient who lacks capacity is given in their best interests in accordance with the Mental Capacity Act 2005. It is notable, however, that the MCA is often not adhered to.

- > Many patients in PDOC may go for years with many major decisions being made and treatments given, but without a single meeting to discuss any of the decisions.
- > This is often due to lack of clarity about who is responsible for holding these discussions, especially when there is more than one doctor involved.

In the absence of a valid and applicable advance decision to refuse the treatment in question, the senior clinician in overall charge of the patient's care is responsible for ensuring that *best interests* discussions are held with the appropriate people.

- > In hospital settings this will usually be the named consultant.
- > Where consultants rotate on a regular basis, it is the responsibility of the trust or hospital management to have a protocol that identifies, at any given time, the individual with overall responsibility for the patient, and to ensure that decisions are not delayed because of regular staff changes.
- > In community settings, responsibility usually lies with the patient's GP.

### Initiating the process

From the outset, all healthcare decisions in people who are unconscious must be made in their best interests. In the immediate hours and days following severe brain injury, the need for rapid decisions, coupled with clinical uncertainty concerning prognosis, may be such that the maintenance and prolongation of life is a predominant determining factor when weighing up a patient's best interests. This early stage of management lies out of the scope of these guidelines and other guidance covers implementation of the MCA in acute and critical care settings.<sup>170</sup>

Nonetheless, it is vital to start collecting information relevant to longer-term planning from the earliest opportunity. This includes establishing the existence of any ADRT, Welfare LPA or Treatment Escalation Plan by asking family and friends, contacting the GP and looking at available hospital records. This information should be available within the first 1–2 days.

Common decisions that are often made without due process in patients in PDOC include:

- > insertion and reinsertion of nasogastric tubes and placement of gastrostomy tubes
- > placing on, or continuing, ventilation
- > inserting a tracheostomy
- > undertaking investigations
- > carrying out surgical procedures, especially neurosurgery
- > treating infections and other intercurrent medical conditions with interventions that carry significant risk.

These and other major decisions about life-sustaining treatments are often required in the first week or two following injury.<sup>171</sup> If a decision has been made not to offer a particular treatment, family members should be informed of this and the reasons for the decision. If the treatment is on offer, then normal *best interests* decision-making process will apply, as described in [Section 4](#). After the first 14 days there can be no excuse for not discussing, properly, any decision of significance.

### *Best interests* decision-making

*Best interests* decision-making is an iterative process that requires revisiting over time as the patient's condition changes, as more information becomes available or as the prognosis becomes clearer. Further *best interests* meetings should be held whenever the need for treatment or planning arises.

Patients who remain in DOC 4 weeks after the onset of severe brain injury fall within the scope of this guidance. By this time, it will usually be possible for most of the relevant medical and social factors to have been explored and considered to start determining the patient's best interests. If this has not yet occurred, a formal *best interests* decision meeting should be held as soon as possible and on any subsequent occasions when important decisions are to be made. All meetings should be arranged with the family / close friends, the Welfare Deputy, or Welfare LPA or IMCA (if one is in place).

*Best interests* decision-making, however, requires properly informed discussion about prognosis for recovery, and other information that some families will find hard to accept. In addition, there may be genuine uncertainty in the early stages – especially where there is a trajectory towards increased responsiveness. The exact timing of *best interests* meetings will depend on the individual circumstances of each patient.

It is generally good practice and easier to establish a shared understanding of the decision-making process in advance of any critical decisions to be made. Box 5.4 sets out some topics for discussion at *best interests* meetings during the various stages of decision-making:

- > In the early phase post-injury, topics for discussion will range around information exchange, which includes establishing a clear understanding of brain injury and the factors that influence prognosis, who is responsible for decisions, how they will be made etc.
- > Subsequently, if it becomes clear that the individual is unlikely to recover a quality of life that they themselves would value, discussion will focus more on the patient's condition and prognosis for recovery, their balance of positive and negative experience, the types of treatment they are receiving (or are on offer) and what would happen if these were to be withdrawn (or not given).

While decision-making starts from the strong presumption that it is in the person's best interests to prolong life, this assumption can be rebutted if there is evidence that the person would not wish to continue to receive it under the circumstances that have arisen.<sup>148</sup>

### Not starting or discontinuing a treatment

It is essential to remember, however, that it is the *giving or continuing*, rather than the withholding or *withdrawing* of a treatment, that needs to be justified and this should be the case with any treatment at any stage.

**Box 5.4 Topics for discussion and documentation in formal best interests meetings**

In the early phase post-injury, topics for discussion will range around information exchange, including:

- > **From the family:**
  - the person him/herself – who they were prior to their injury, and what is known about their prior values and beliefs.
- > **From the team:**
  - a general background to severe brain injury, recovery and prognostic factors
  - the process of assessment
  - the type of decisions that may need to be made and when
  - who the decision-makers are for the various decisions to be made at the appropriate times
  - how they will be made and how the family will be involved.
  - the types of decisions that may need to be made and their approximate timescales.

Subsequently, if the patient remains in PDOC, the topics for discussion will focus more on:

- > their current condition – level of awareness and quality of life
- > their balance of positive and negative experiences
- > their prognosis for further recovery or change, and the degree of certainty with which that can be predicted
- > the types of life-sustaining treatment they are still receiving
  - the likelihood that the patient would want to receive them if able to say for themselves
  - what would happen if these were to be withheld
    - or, if already started, if they were to be withdrawn.

**Documentation should include:**

- 1 Any treatment decisions needed, or likely to be needed, within the foreseeable future should be identified and separated into:
  - > routine decisions unlikely to be altered (eg simple symptomatic treatments)
  - > immediate major decisions that may arise, in particular ACPR and the treatment of life-threatening events
  - > elective major decisions with potential benefits or risks that affect survival and/or quality of life (eg elective placement of a PEG tube, operation to treat another injury).
- 2 How the decision was reached
  - a who was consulted
  - b what known factors may influence the decisions.
- 3 What the decisions are, with a justification for each.

When further *best interests* meetings should be held – either as a routine or to discuss a particular decision if it is needed.

It is important to frame decisions not to start or continue a life-sustaining treatment appropriately.

- > Such decisions are not, and never should be, considered as a judgement that the person 'would be better off dead', or that one is choosing 'to kill the person' as a lay-person might perceive it.
- > But for the injury underlying the PDOC, the patient would not need most, if not all, of the life-sustaining interventions they are having, so to say that removing or not starting them is the cause of a person's deterioration or death is factually incorrect.
- > An increased likelihood of death, amounting sometimes to a certainty, is a recognised consequence of not giving some treatments, but that is not the intention of the decision-maker.
- > Many people with terminal illness choose not to continue active treatment knowing that they may die sooner. Few would actually say that they wish to die; most will say that they wish to focus on the quality of their remaining days rather than the quantity.

Once again, family members, friends, and other informants must be made fully and unequivocally aware that responsibility for the final decision lies with the clinical team and not with themselves.

### Documentation, and dissemination

Properly held *best interests* meetings take time and resources. To avoid having unnecessary further meetings, this investment should be used to its fullest extent by ensuring that the information shared, and the resulting decisions, are made available to all who may need to know.

- > A detailed record should be kept of all *best interests* meetings, summarising the information exchanged and clearly documenting any decisions reached and the justification for them.
- > Notes should be circulated to all parties present, who should be given the opportunity to dispute any points of factual accuracy before they are finalised.
- > In addition (subject to consent from all those present), it may be helpful to make a digital recording of formal *best interests* meetings and share a copy with all relevant parties. This enables family members to listen again to the information in their own time and enables those who could not attend to hear what was said at first hand. It also ensures that a full and accurate record of the meeting is available to all parties immediately.

Once finalised, documents recording *best interests* decision meetings should be disseminated to all parties and passed on to other teams and organisation who may take on responsibility for the patient at some later time. Those parties should respect the decisions until and unless a further meeting, properly constructed and run, alters any decisions.

## Section 5a Summary of recommendations

Recommendation	Grade
<p><b>5.1.1 Decisions regarding treatment escalation and life-sustaining treatment</b></p> <p>As part of clinical treatment planning for patients with serious illness or injury, the treating team should consider and document decisions regarding life-sustaining treatments including</p> <ul style="list-style-type: none"> <li>&gt; escalation or unplanned interventions for life-threatening events that may / may not arise</li> <li>&gt; longer-term medical interventions designed to sustain or prolong life.</li> </ul> <p>For each treatment clinicians should first consider the likelihood that treatment will be effective or futile, and whether or not to offer it. The overall clinical responsibility for decisions to offer life-sustaining interventions rests with the most senior clinician in charge of the patient's care but, wherever possible, should be agreed with the whole treating team. If the treatment <i>is</i> on offer, clinicians should consider:</p> <ul style="list-style-type: none"> <li>&gt; whether it is covered by the terms of appointment of an ADRT or Welfare LPA</li> <li>&gt; whether it is in the patient's best interests to start or continue, taking into account: <ul style="list-style-type: none"> <li>– the benefits, burdens and risks of treatment</li> <li>– the patient's likely wishes.</li> </ul> </li> </ul>	E1/2
<b>Immediate and urgent interventions: ACPR and treatment escalation planning</b>	
<p><b>5.1.2 Planning in advance</b></p> <p>Patients in PDOC may become unwell suddenly and unpredictably.</p> <ul style="list-style-type: none"> <li>&gt; The decision to offer invasive and potentially harmful treatment must be considered on each individual's presentation and circumstances.</li> <li>&gt; Advance treatment planning is particularly important for decisions that may require rapid 'out-of-hours' intervention by emergency teams who are unfamiliar with the patient.</li> </ul>	E1/2
<p><b>5.1.3 Benefits and harms of ACPR in patients in PDOC</b></p> <p>Clinicians responsible for the care of patients with PDOC should be aware that:</p> <ul style="list-style-type: none"> <li>&gt; ACPR in general has a very low success rate and may have harmful side effects, and even short periods of hypoxia are likely to lead to further brain damage and a worse clinical outcome.</li> <li>&gt; For the large majority of cases, ACPR represents 'futile' treatment for which the harms outweigh the benefits. It is seldom justified and appropriate in patients with continuing PDOC.</li> </ul>	E1/2
<p><b>5.1.4 Making ACPR and DNACPR decisions</b></p> <ul style="list-style-type: none"> <li>&gt; ACPR and DNACPR decisions should be considered as a matter of routine practice for patients with continuing PDOC but should be</li> </ul>	E1/2

Recommendation	Grade
<p>normalised as part of treatment escalation planning in line with the ReSPECT process (see Recommendation 5.1.6).</p> <ul style="list-style-type: none"> <li>&gt; After such a decision is made, a 'DNACPR form' or equivalent Treatment Escalation Plan should be used to communicate the decision to all those involved in the patient's care.</li> <li>&gt; Distinction should be made between decisions to attempt or withhold CPR and other forms of emergency treatment, such as:               <ul style="list-style-type: none"> <li>– a short reversible event, eg blocked tracheostomy tube or transient arrhythmia</li> <li>– an acute infective episode</li> <li>– other treatment, eg for seizures etc.</li> </ul> </li> <li>&gt; Advance instructions / treatment plans should be made distinctly and separately for each different circumstance.</li> <li>&gt; Once a DNACPR decision has been made, there should be a continuity of that decision across all settings including acute care, nursing home and ambulance transport, until and unless formally reviewed.</li> <li>&gt; All DNACPR decisions should be reviewed at appropriate intervals and should at a minimum form part of the annual review process.</li> </ul>	
<p><b>5.1.5 Informing family members about DNACPR decisions</b></p> <p>If ACPR is considered by the medical team to be a futile or clinically inappropriate treatment, the clinician is under no obligation to offer it. However, the family should be informed of the decision unless it is not practicable or appropriate to do so.</p> <p>The fact that it may distress the family is not sufficient reason not to inform them. There must be a presumption in favour of doing so.</p> <p>If the doctor decides to make a DNACPR decision without discussion with the family, the reasons for this should be documented and it is wise to seek a second opinion from a consultant colleague.</p>	<p><b>E1/2</b></p>
<p><b>5.1.6 Treatment Escalation Plans</b></p> <p>Clinicians should consider the range of other unplanned life-sustaining interventions that may be applicable to the patient.</p> <p>A written Treatment Escalation Plan (TEP), should be drawn up in discussion with the patient's family and placed prominently in the patient records (See exemplar in electronic <a href="#">Annex 5a</a>).</p>	<p><b>RB<sup>164</sup></b></p> <p><b>E1/2</b></p>

	Recommendation	Grade
	TEPs should be reviewed at regular intervals and in the light of any change in the patient's condition.	
<b>Elective and long-term life-sustaining treatments</b>		
5.1.7	<p><b>Longer-term medical interventions designed to sustain or prolong life may include:</b></p> <ul style="list-style-type: none"> <li>&gt; prophylactic treatments or screening to protect against future illness</li> <li>&gt; long-term treatments to compensate for organ dysfunction (eg dialysis, tracheostomy, assisted ventilation, insulin)</li> <li>&gt; CANH.</li> </ul> <p>In the absence of a valid and applicable ADRT, all treatments that are given must be on the basis of the patient's best interests, either supporting a Welfare LPA (if there is one) to make the decision, or weighing up the likely benefits and harms in conjunction with family members to determine the patient's likely views and wishes.</p> <ul style="list-style-type: none"> <li>&gt; In general, treatments that are given to control symptoms and improve ease of care remain appropriate.</li> </ul> <p>However, once it becomes clear that the patient is unlikely to recover a quality of life that they themselves would value, then the harms of continued life-sustaining treatment are likely to outweigh the benefits, and it is necessary to consider their withdrawal.</p>	E1/2
5.1.8	<p><b>Withdrawal of life-sustaining treatment</b></p> <p>The majority of decisions regarding life-sustaining treatment can be made through local <i>best interests</i> decision-making involving the family and treating team:</p> <ul style="list-style-type: none"> <li>&gt; Planned withdrawal of CANH: <ul style="list-style-type: none"> <li>– When considering planned withdrawal of CANH, clinicians should follow the procedures set out in <b>Section 4</b>.</li> </ul> </li> <li>&gt; Planned withdrawal of other long-term life-sustaining treatments: <ul style="list-style-type: none"> <li>– Although not mandated for treatments other than CANH, clinicians considering planned withdrawal of other long-term treatments where death is expected to follow within a few days or weeks after they are stopped, are advised to use the framework for proportionate external review set out in Table 4.2 to determine the appropriate level of scrutiny.</li> </ul> </li> </ul>	E1/2
<b>Practical <i>best interests</i> decision-making about life-sustaining treatment</b>		
5.1.9	<p><b>Responsibility for treatment decisions</b></p> <p>In the absence of a valid and applicable ADRT, the senior clinician in overall charge of the patient's care is responsible for ensuring that <i>best interests</i> discussions are held with the appropriate people involved.</p> <ul style="list-style-type: none"> <li>&gt; At any point in the patient's care pathway it should be clear with whom this responsibility lies: <ul style="list-style-type: none"> <li>– in hospital settings this will usually be the named consultant.</li> </ul> </li> </ul>	E1/2

Recommendation	Grade	
<ul style="list-style-type: none"> <li>&gt; Where consultants rotate on a regular basis, the trust or hospital management is responsible for ensuring that decisions are not delayed because of regular staff changes.                             <ul style="list-style-type: none"> <li>– in community settings, responsibility usually lies with the patient’s GP.</li> </ul> </li> </ul>		
<b>5.1.10</b>	<b>Obtaining information about the patient’s likely wishes:</b>	<b>E1/2</b>
<p>Information relevant to longer-term planning should be collected from the earliest opportunity</p>		
<ul style="list-style-type: none"> <li>&gt; Within the first few hours/days, the clinical team should establish the existence of any ADRT, Welfare LPA or Treatment Escalation Plan by asking family and friends, contacting the GP and looking at available hospital records.</li> <li>&gt; In the absence of these, within the first 2 weeks after onset of coma/DOC, the healthcare team should discuss with family members and/or close friends:                             <ul style="list-style-type: none"> <li>– the patient’s prior values, beliefs, wishes and feelings</li> <li>– any other factors the patient is likely to have considered when making a healthcare decision.</li> </ul> </li> </ul>		
<b>5.1.11</b>	<b>Normalising <i>best interests</i> decisions about life-sustaining treatments</b>	<b>E1/2</b>
<ul style="list-style-type: none"> <li>&gt; Explanation of decisions about life-sustaining treatment should be seen so far as possible to be normal, by being part of more a general <i>best interests</i> discussion with the patient’s family/close friends.</li> <li>&gt; This should form part of the routine exchange of information at an early stage in the patient’s admission.</li> <li>&gt; Unless one of the family is a Welfare LPA, whose terms of appointment expressly cover decisions about life-sustaining treatment, it should be made clear to the family that:                             <ul style="list-style-type: none"> <li>– these decisions lie with the senior clinician responsible for the patient’s care</li> <li>– the family is not being asked to make the decision, but are simply being asked about the patient’s likely views and wishes</li> <li>– the main question is ‘What would the patient have decided and why, were s/he able to make the decision?’</li> </ul> </li> </ul>		
<b>5.1.12</b>	<b>Formal <i>best interests</i> meeting</b>	<b>E1/2</b>
<ul style="list-style-type: none"> <li>&gt; If the patient has been in DOC for 4 weeks, they are defined as being in a prolonged DOC.</li> <li>&gt; If this has not yet happened, the healthcare team should convene a formal <i>best interests</i> meeting as soon as possible with the family / close friends (and the Welfare LPA, Deputy or IMCA if one is in place) to discuss and document the factors relevant to best interests.</li> <li>&gt; Background information should be provided about:                             <ul style="list-style-type: none"> <li>– severe brain injury, recovery and prognostic factors</li> <li>– the type of decisions that may need to be made and when</li> <li>– who is responsible for the decisions</li> </ul> </li> </ul>		

Recommendation	Grade
<ul style="list-style-type: none"> <li>- how the family will be involved.</li> <li>&gt; The meeting should consider decisions concerning any emergencies likely to arise in the near future, and any immediate views about longer-term treatments.</li> <li>&gt; Further <i>best interests</i> meetings should be held:               <ul style="list-style-type: none"> <li>- at a planned reasonable interval, eg 2–3 months from the initial meeting</li> <li>- when circumstances already agreed in advance arise</li> <li>- whenever an unforeseen or important new decision needs to be made</li> <li>- whenever it becomes clear that the patient is unlikely to recover to a condition that they themselves would consider as providing an acceptable quality of life.</li> </ul> </li> </ul>	
<b>5.1.13</b> Documentation	<b>E1/2</b>
<ul style="list-style-type: none"> <li>&gt; A detailed record should be kept of all <i>best interests</i> meetings, summarising the information exchanged and clearly documenting any decisions reached and the justification for them.               <ul style="list-style-type: none"> <li>- Notes should be circulated to all parties present, who should be given the opportunity to dispute any points of factual accuracy before they are finalised.</li> <li>- If all present agree, <i>best interests</i> meetings may be digitally recorded. In this case, a copy should be shared with all relevant parties.</li> </ul> </li> <li>&gt; Once finalised, documents recording <i>best interests</i> decision meetings should be disseminated to all parties and passed on to other teams and organisation who may take on responsibility for the patient at some later time.</li> <li>&gt; Those parties should respect the decisions until and unless a further meeting, properly constructed and run, alters any decisions.</li> </ul>	
<b>5.1.14</b> Training and practical experience	<b>E1/2</b>
<p>Practical experience in holding <i>best interests</i> discussions regarding treatment escalation planning and decisions to start, continue or stop life-sustaining treatment should form an essential part of medical training programmes for specialties likely to be involved in managing patients with profound brain injury, including PDOC – eg rehabilitation medicine, neurology, neurosurgery, geriatric medicine, critical care, general practice etc.</p>	

## Section 5b

# Practical management of end-of-life care for patients with PDOC

### Challenges for end-of-life care

Patients dying in VS/MCS pose a number of challenges for management. These include the following:

- > The process of dying is often prolonged and timing of death difficult to anticipate – there is often uncertainty over when to apply the end-of-life care pathways even after elective withdrawal of life-sustaining treatments.
- > Patients with profound brain injury typically have complex spasticity and involuntary movements requiring skilled postural handling techniques and specialist equipment often not available in standard hospice settings.
- > Some patients in PDOC have autonomic dysfunction and/or automatic/reflexive movements that may become more prominent with metabolic disturbance during the dying process. Even when the patient him/herself is unaware these may give the appearance of suffering which is distressing for family and care staff to witness
- > Some have underlying painful conditions and, particularly those in MCS, may experience distress but not have the means to communicate their symptoms.

Managing end-of-life care in this situation often challenges care staff and families to their limits. For all these reasons, end-of-life care for patients with VS or MCS requires a team-based approach with close coordination between specialists in palliative care and neurodisability management. The combined skills of both specialties are required to optimise medication, to support distressed family members, and also to support the care team.

### Mode of death

As highlighted in [Section 4](#) (Table 4.2), there are several categories of patient who may die in PDOC:

- > **Category 1:** Patients for whom death is imminent as a result of other causes such as infection, complications of the brain injury (eg acute hydrocephalus, raised intracranial pressures, bleeding etc) or other intercurrent conditions that may be unrelated to the brain injury.
- > **Category 2:** Those with other comorbidities or frailty that will inevitably result in death, not necessarily imminently but most probably in less than 1 year.

- > **Categories 3–5:** Those with a stable or upward trajectory who may live for a number of years (or even decades), but for whom a decision has been made that continued life-sustaining treatment (including CANH) is not in their best interests.

It is important to distinguish them because they may be expected to die differently when life-sustaining treatments are stopped.

Patients in category 1 are expected to die within hours or days from the underlying condition. The fact that they are in PDOC has, in effect, become incidental because it contributes little or nothing to their death, although the effects of severe brain injury (eg spasticity, involuntary movements etc may require specific management). Their palliative needs will generally be similar to those of patients without PDOC and are familiar to specialist palliative care teams and hospices. They can usually be managed with conventional palliative care approaches, medications and dosing regimens and will generally die in less than 14 days.

For patients dying following withdrawal of life-sustaining treatment in categories 2–5, the mode of death, and thus the symptoms requiring palliation, will depend on any underlying conditions, and the type(s) of treatment that are withdrawn. For example:

- > aspiration pneumonia, bronchopneumonia, and respiratory failure may follow withdrawal of assisted ventilation and/or a tracheostomy
- > ketoacidosis will typically follow withdrawal of insulin
- > renal failure, uraemia and hyperkalaemia follow withdrawal of dialysis.

Acidosis and metabolic disturbance are common end-stage features in many of these situations. CANH is usually withdrawn at the same time because it increases the risk of vomiting, as well as exacerbating hyperglycaemia, hyperkalaemia etc and in that sense could actually hasten death.

If CANH alone is withdrawn in otherwise medically stable patients (categories 3–5), the patient will develop dehydration and multiorgan failure, including renal failure, with acidosis, uraemia and other metabolic and electrolyte disturbances that end ultimately in cardiorespiratory arrest. This process typically takes about 2–3 weeks during which they will visibly lose weight and change in appearance. Reduced tissue perfusion may also affect absorption of subcutaneous medications. Families and care teams should be advised to expect this and supported through the process.

### Physiological hyperactivity

Although the majority of patients will die peacefully, some may show a strong physiological reaction to the altered homeostatic balance resulting from acidosis and metabolic disturbance.

A proportion of patients with profound brain injury have dysautonomia leading to ‘un-damped’ homeostatic responses. In this situation, reflex physiological signs and hyperactivity in the brainstem can be extreme and unstable.

The following signs may be expected:

- 1 Sweating, tachycardia, agitation etc which can be dramatic.
- 2 Hyperventilation secondary to metabolic acidosis. If this occurs with partially closed vocal cords, then the patient will make audible sounds, such as groaning.
- 3 Other spontaneous and reflex movements that the person ordinarily displays such as roving eye movements, grimacing, crying, teeth grinding, chewing etc may become much more pronounced.

To the onlooker these can give the impression that the patient is aware and experiencing distress. The burden of witness will be profound and should never be underestimated.

Although this affects a relatively small minority of patients, it is important to be aware of the possibility, to understand the reasons for it and so be prepared to manage it proactively when it happens.

- > Palliative care plans should make contingency for this occurrence.
- > Families/care staff require considerable explanation and support including aftercare for bereavement support, and staff debriefing.

### End-of-life care following withdrawal of life-sustaining treatment

Dying following the withdrawal of life-sustaining treatment in patients who are otherwise stable poses some particular challenges.

#### Family and staff experience

While the cause of death is the original brain injury (see [Section 4](#)), families and staff on the ground may understandably perceive withdrawal of medical treatment as the cause of death because it is the most proximate event. Perceptions such as these contribute to the burden of witness for families and for staff inexperienced in end-of-life care.

Families have to contend with the decision-making process, the anxiety and apprehension accompanying a death that may take anything from days to weeks.

- > Those who wish to maintain a bedside vigil can become physically and emotionally exhausted if the dying process is prolonged, and many are distressed by the physical changes that this entails (see below).
- > Although some families have reported a sense of relief that death was 'surprisingly good', 'in accord with [the patient's] wishes' and led to 'a sense of closure',<sup>172</sup> not all deaths are straightforward.

Clinical staff may also feel distressed, especially where they have provided diligent care over a number of months or years and come to know the patient.<sup>173</sup>

#### Challenges for palliative care

The aims of palliative care are to achieve the best quality of life as people live and then to provide calm, peace and dignity as they die.

Because patients with PDOC are often young and relatively fit, in contrast to many other terminal conditions, dying may take anything from days to weeks and that timing is uncertain.

- > Enduring a prolonged dying process can be very difficult, not only for the family but also the for attending care staff.
- > Non-specialist staff often require reassurance, because many are used to seeing the patient die within days of entering an end-of-life care pathway.

#### Suitable settings for end-of-life care

Patients dying in PDOC require management by care and nursing staff who are experienced in dealing with the needs of patients with profound neurological disability as well as palliative care (many specialist nurses and AHPs are non-medical prescribers). The choice of setting for

withdrawal of life-sustaining treatment matters and requires careful consideration, based on the patient's individual needs and presentation.

### Dying at home or in a nursing home

It is rarely possible to provide the level of support required to allow patients to die within their own home. For patients who have little or no awareness of their environment, the importance of dying in their own home is usually less critical than the more immediate concerns described above, although it may be important for some families.

When patients have been in long-term nursing home care, it is not uncommon for care teams to want to provide their end-of-life care as well. However, the practical challenges must not be underestimated as the intensity of input required usually makes effective end-of-life care impractical unless it is a specialist care home with ready access to medical input out of hours.

When end-of-life care is provided in specialist nursing homes, the programme should be supported by a staff with the appropriate skills and knowledge of patients dying in PDOC and have access to both specialist neurodisability and palliative care advice. It is essential that both the staff and family understand and are prepared for the challenges that may sometimes arise.

### Specialist settings and support for local services

Any hospice providing this care should have access to specialists in complex neurological disability. A small number of hospices have established specific experience and skills in this area, usually because of their proximity to neurorehabilitation or trauma centres. If the hospice team has not had prior experience of caring for patients dying in PDOC, it is also important that they are well briefed in advance and have ready access to advice from colleagues with specific experience.

Patients in categories 3–5 in particular should usually be managed in settings with experience in the management of both complex neurodisability and neuropalliative care, supported by specialist palliative care services.<sup>174</sup>

For patients in higher-level MCS, or at risk of developing physiological hyperactivity, the potential need for rapid escalation to IV medication if necessary is beyond the resources even of many hospices and is likely to require management in a hospital-based specialist neuropalliative care centre

We therefore recommend that elective withdrawal of CANH should be organised by specialist neurorehabilitation and palliative care teams working closely together. The setting will depend upon individual circumstances including:

- > the experience of the current setting and team
- > the likelihood of the complications described above occurring
- > access to specialist support and escalation
- > the wishes of the family and the current care team.

Sometimes admission to a highly specialist centre will be needed, either before starting withdrawal or during the process, and currently a small number of such services exist and are building up experience in this unusual and challenging area of care.

If withdrawal is managed locally (eg in a hospice or nursing home setting):

- > staff must ensure before starting the process of withdrawal that they will have access to specialist advice and support from staff with specific expertise in this area
- > commissioning arrangements are in place, in advance, to support
  - the provision of appropriate specialist support
  - rapid transfer to a specialist unit, in the event that this is necessary.

(By the time the need arises it is usually urgent, and it is clearly inappropriate to arrange transfer through standard emergency services, emergency departments etc).

### Support for families and clinical teams

Death following withdrawal of CANH in patients who are otherwise stable is a particularly emotive issue for reasons that have been outlined above. Families and care teams who are considering this issue frequently ask questions that can be challenging to answer. Box 5.5 contains some responses that may help clinicians to provide consistent information. Much of this information is also applicable to (or can be adapted for) patients dying from withdrawal of other life-sustaining treatments.

### Use of sedation and analgesia – calm coma

Irrespective of their cognitive capacity, patients in PDOC are entitled to dignity and respect, and any signs that are suggestive of distress or suffering should be assumed to be such. An overriding concern of many families and clinicians is that patients dying following the withdrawal of life-sustaining treatment may experience pain, discomfort or distress and be unable to communicate this. Withdrawing CANH tends to cause particular anxiety because of concern that patients might experience thirst and hunger. Even if they are not capable of experiencing symptoms or emotions, some level of sedation and analgesia must be given to provide absolute assurance to family members and staff that the patient is not suffering.

Many patients are on quite extensive treatment regimens for symptoms such as spasticity or seizure control. Discontinuation of these medications may lead to exacerbation of these unwanted symptoms, but their continuation via PEG may involve significant quantities of fluids and so unnecessarily prolong the dying process. Parenteral (subcutaneous or intravenous) palliative care regimens comprising opiates, benzodiazepines and/or barbiturates can provide effective replacement, but the starting dose will need adjustment to allow for this. Titration to calm coma using analgesics and sedation is the simplest and most pragmatic solution to ensure effective management without overdosing.

Protocols are detailed below but three areas need clarity:

- > **Opioids are analgesics and not sedatives.** They can provide effective relief of pain and discomfort, but will not be effective for apparent distress (eg due to physiological hyperactivity). The regimens that we recommend therefore include both opioids and sedatives and are familiar to palliative care physicians.
- > **Clinicians are naturally cautious and anxious to avoid the risk of being accused of deliberate overdosing.** Consequently, and despite strong evidence that opioids and strong sedative drugs may be given safely in dying patients.<sup>175</sup> It is quite common that medication is not increased quickly or high enough to control escalating signs of physiological hyperactivity. In the context of acidosis, (which is typically present in this situation) increased respiratory drive mitigates any risk of depressing ventilation that might otherwise occur with high-dose sedative medication.

That said, symptoms of physiological hyperactivity to metabolic disturbance following CANH withdrawal typically escalate in the later stages. Titration of medications and the use of bolus doses to manage these symptoms will necessarily occur on occasion close to, or immediately prior to, death. These are open to being misinterpreted as the final act bringing about death, simply because of their temporal proximity to it. Where drug doses are necessarily escalated to control symptoms, they are neither lethal nor harmful.<sup>175</sup> The staff who administer these regimens need to be supported and helped to know that, in law, they are treated as being coincidental to dying and not the cause of it.

- > **Most sedative drugs used in palliative care act, at least in part, through modulation of higher cortical function.** In the presence of profound cortical dysfunction, they may be ineffective even in exceptionally high doses. Therefore, to achieve a state of ‘calm coma’ and a peaceful and dignified death:
  - a appropriate escalation may need to be rapid and considerable, especially where the parenteral palliative regimen replaces pre-existing medications
  - b there are particular concerns for patients in higher level MCS whose ability to experience pain and discomfort is likely to be unimpaired, that will require support from specialist palliative care teams with expertise in such cases
  - c intravenous administration may be required to achieve symptom control. However, this requires an appropriately skilled nursing and medical team on site, which is usually only available in hospital settings.

While the majority of treatment withdrawals pass without incident and use drug doses well within conventional ranges familiar to specialist palliative care, inexperienced physicians should not attempt to manage elective withdrawal of life-sustaining treatment without the support of a specialist team with direct expertise in this area. In cases where this form of terminal care is initiated outside a specialist unit or hospice, back-up arrangements should be in place for immediate escalation of care without any delays waiting for funding or gaining ‘agreement’ from the specialist supporting team, should this become necessary.

**Box 5.5 Frequently asked questions and answers about withdrawal of CANH**

Families considering the issue of withdrawing CANH for their loved one frequently ask questions that can be challenging to answer. The following FAQs may assist clinicians to respond.

**What will [name] die of?**

Ultimately s/he will die because s/he has a very severe brain injury and are unable to sustain his/her own food and fluid intake. Following withdrawal of CANH, the body has no source of fluid and the normal mode of death is by dehydration. With advanced dehydration, the circulating blood volume drops and metabolites accumulate, compromising the vital organs and ultimately causing multiorgan failure affecting the kidneys, liver, heart, lungs and brain.

**How long will it take for [name] to die?**

It is difficult to predict exactly, but experience suggests that for patients like [name] who die following withdrawal of CANH, death will usually occur within 2–3 weeks. Sometimes it is quicker (for example if they develop an intercurrent infection or seizures), but it is rarely longer than this.

**Why must [name] die from deprivation of food and fluid – could he/she just have a quick lethal injection?**

English law identifies a clear difference between withholding life-sustaining treatment without which a person will die, because it is permitting an existing and established fatal process to run its course, even though this may be quick. Active killing by means of a lethal injection is a separate intervention. Euthanasia is illegal under English law, and no doctor could prescribe or administer a lethal injection. However, with excellent palliative care and attention to detail we aim to ensure that [name] will not suffer in any way and will have as peaceful and dignified a death as possible.

**Will [name] experience pain or suffering?**

For patients in VS: From studies of patients who die of dehydration but remain conscious, death by dehydration appears to be relatively painless. In addition, so far as we can tell, [name] has no awareness of him/herself or anything around him/her and therefore will not suffer in any way. You may notice an increase in reflex behaviour (such as sweating, increased movements, moaning/groaning etc), which may give the impression that s/he is in pain. So, in order that we can all be absolutely certain s/he is not suffering we will prescribe strong sedative and pain-relieving medication to keep him/her calm and allow him/her a peaceful and dignified death.

For patients in MCS: This is a potential concern, although studies of patients who die of dehydration but remain conscious suggest that death by dehydration is not painful. Nevertheless, because [name] cannot readily communicate to tell us what s/he is experiencing, and in order to ensure that s/he is not suffering in any way, we prescribe strong sedative and pain-relieving medication to keep him/her calm and free from pain and discomfort. We will work very closely with the palliative care team to ensure that symptom control is optimised so that s/he can have a peaceful and dignified death.

**[Name] has always carried a donor card – can his/her organs still be donated?**

Unfortunately, organ donation is not possible after withdrawal of CANH as the mode of death is through multiorgan failure secondary to dehydration, and the large majority of the relevant organs have been irreversibly damaged.

### Routes of administration

The enteral route does not provide reliable drug absorption because of gastric stasis and the risk of vomiting. Moreover, when enteric access is maintained there have been cases where well-meaning staff have covertly administered fluid or flushes. Therefore, when CANH is withdrawn (either as a primary decision to withdraw life-sustaining treatment or as part of the end-of-life programme in category 1 patients) the PEG should either be removed or permanently sealed off and all medications given through subcutaneous (SC) or intravenous (IV) routes.

**Continuous subcutaneous infusion (CSCI)** is the usual mode of drug administration in palliative care. However, absorption is slower and less predictable than the IV route. While this is unlikely to present difficulties for category 1 and 2 patients, it can be a problem in categories 3–5 patients in whom profound dehydration is the norm in the late stages of elective withdrawal of CANH.

**IV infusion (IVI)** in categories 3–5 carries the advantage of predictability, especially as dehydration becomes more pronounced. It also ensures a more immediate effect for boluses to cover short-term interventions, such as oral hygiene and turning. This tighter control often results in lower overall doses of medication. In hospital settings, where IV lines and administration are part of normal practice, some specialist units now use this route as a matter of routine.

The choice of route will be influenced by

- > the setting, facilities and skills available
- > the preferences and experience of treating clinicians,
- > the individual needs of the patient.

In many cases, CSCI regimens may be entirely sufficient to support a peaceful death, especially in uncomplicated cases, but others may require IV medication to gain adequate control.

Unfortunately, in the context of CANH withdrawal, this need may arise only in the later stages of profound dehydration, by which time hypovolaemia can make it difficult to gain reliable venous access.

- > On the basis of current evidence, there is no reliable way to predict which patients are likely to be affected, but underlying painful conditions with high PDOC pain scores, dysautonomia, or marked automatic movements – especially if in higher-level MCS – should carry a higher index of suspicion.
- > In these category 3–5 cases it is particularly important to make contingency arrangements for escalation if palliative care regimens are started subcutaneously.
- > If the patient is in hospital, or a specialised hospice, it may even be appropriate to consider securing venous access pre-emptively using a peripherally inserted central catheter (PICC) or mid-line. This is unlikely to be feasible in the community.

Proactive IV access is also justified if there is the risk of rapidly escalating symptoms. For example, in the withdrawal of assisted ventilation or de-cannulation of a tracheostomy, sudden respiratory distress is a real possibility.

This may require advance planning in liaison with the anaesthetic team and/or the hospital Drugs and Therapeutic Committee to ensure that all the requisite policies and procedures for IV

administration are in place ahead of time and that the correct medications are immediately available.

Tables 5.2a, b and c provide the outline for a staged palliative care regimen.

- > Table 5.2a outlines the principles and prerequisites.
- > Table 5.2b details a staged escalation for SC administration.
- > Table 5.2c details the equivalent staged escalation for IV administration.

These protocols are for guidance only and will vary according to need. For example, as noted above, higher doses of midazolam or phenobarbitone may be necessary to replace complex anticonvulsant regimens or address problems of severe spasticity. This is a matter for individual judgment and collaborative decision-making between the palliative care and neurodisability teams.

### Certification of death

The BMA/RCP guidelines<sup>4</sup> provide detailed advice (p43) about drawing up a death certificate after withdrawal of CANH.

It is the responsibility of the senior clinician in charge of the patient's care to ensure that the death is properly certified and reported, following established procedures. Following withdrawal of CANH, the immediate, direct cause of death will usually be multiorgan failure or bronchopneumonia, whereas the underlying cause of death will be the original brain injury or medical condition.

The usual rules will apply for determining whether a particular death needs to be reported to the coroner and will depend on the cause of the brain injury or condition.<sup>176</sup> The role of the coroner is to investigate where the deceased died a violent or unnatural death, the cause of death is unknown, or the deceased died while in custody or otherwise in state detention.

If the senior clinician is uncertain as to whether a death should be reported to the coroner or not, he or she should contact the coroner's office. A National Medical Examiner system is being rolled out across England and Wales to provide proper scrutiny to ensure accuracy of certification and appropriate direction of deaths to the coroner, as well as better support to the bereaved (<https://improvement.nhs.uk/resources/establishing-medical-examiner-system-nhs/>).

If a case is directed to the coroner, the GDG recommends that the paperwork supporting the *best interests* decision to withdraw CANH should be provided to the coroner, as the information contained in it may provide useful clinical background and help to avoid causing further distress to families by having to go over the issues again.

**Table 5.2a Principles and pre-requisites of the palliative care regimen**

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<b>Arrangements</b>	<p>Ensure that:</p> <ol style="list-style-type: none"><li>All staff are fully briefed and understand:<ol style="list-style-type: none"><li>the principles of end-of-life care in this unusual situation</li><li>the uncertainty of the duration and course of the dying process.</li></ol></li><li>All the necessary equipment (eg syringe pumps) and medications are available to deliver the regimens in Tables 5b or c.</li><li>The family has been given information about what to expect and that arrangements are in place to support them, keep them informed and answer any questions that may arise.</li><li>Arrangements are in place for:<ol style="list-style-type: none"><li>regular medical review (several times a day if necessary, including out-of-hours advice)</li><li>active support from a specialist team or teams covering both neurological rehabilitation and palliative care.</li></ol></li><li>If starting outside a specialist environment, funding and practical arrangements are in place to support escalation and transfer without delay, should this become necessary.</li></ol>
<b>Preparations</b>	<ol style="list-style-type: none"><li>If the IV route is chosen, establish long-term IV access using a PICC or mid-line.</li><li>Stop feeding and remove or seal off the PEG tube.</li><li>Review any medications for which the indications continue (eg antispasmodics, anticonvulsants) and consider the most suitable alternative route or replacement drug for these symptoms.</li><li>If morphine and midazolam are considered appropriate replacement drugs, the starting doses in stage 1 may need to be adjusted accordingly.</li><li>Apply the usual local processes for care of the dying.</li><li>Sedating medication may be given by CSCI or IVI via a syringe pump. If given SC, arrangements should be in place to transfer to IV administration if necessary.</li></ol>
<b>Principles</b>	<ol style="list-style-type: none"><li>Medication can either be given:<ol style="list-style-type: none"><li>SC with a single infusion and SC boluses as needed.</li><li>(If phenobarbitone is the sedative of choice, this will need to be administered in its own syringe pump).</li><li>IV with a separate infusion of each drug (if necessary) and IV boluses delivered from each infusion pump as required.</li></ol></li><li>Bolus doses (given SC or IV) may be used to assess the effect on unwanted signs and allow escalation of the effective medication.</li><li>Medical staff should review the patient at least 3–4 times per day to ensure adequate symptom relief and adjust the infusion dose according to the frequency of bolus doses required.</li><li>Never decrease the background infusion dose, even when symptoms/signs appear to be well controlled.</li><li>If the patient is not responding to bolus doses, either maximum benefit has been reached or it is not being absorbed.<ul style="list-style-type: none"><li>If still on a CSCI regimen, give a trial bolus of IV and transfer to IVI if a response is seen.</li><li>If already on IVI and there is no response to IV bolus, proceed to next the stage of the protocol.</li></ul></li></ol>

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Table 5.2b Staged escalation of palliative care regimen using SC administration

Stage	Description	Escalation
<b>Stage 1 continuous SC infusion</b>	Set up a syringe driver and commence continuous SC infusion with: <ul style="list-style-type: none"> <li>&gt; midazolam 10 mg/24 hours and</li> <li>&gt; morphine 10 mg/24 hours.</li> </ul>	
Bolus doses	Prescribe 2.5–5 mg SC bolus doses (as needed) of each drug for management of signs/symptoms of physiological distress. Nursing staff to administer the SC doses <b>and assess</b> if the desired effect is achieved. <ul style="list-style-type: none"> <li>– If no response after 15–30 minutes to initial bolus, repeat the same dose.</li> <li>– If still no response after 30 minutes double the bolus dose.</li> <li>– If no response after 30 mins repeat the double dose.</li> </ul> Bolus doses can also be given <b>prior to interventions</b> that provoke unwanted reflex activity.	
If requiring bolus doses <b>and responding</b>	Re-prescribe the total dose of each drug for the previous 24 hours* as the baseline CSCI up to maximum dose of 100 mg/24 hours midazolam and 150–200 mg/24 hours morphine.	If required, give further bolus SC doses, as needed. Double bolus doses may be tried for effect if a single bolus gives a suboptimum response.
If <b>no response</b> to SC midazolam	Convert to IVI route or progress to add levomepromazine or phenobarbitone according to preference / local guidelines. Try a test bolus dose in the first instance. If a response is observed set up an infusion as per below	
<b>Stage 2 continuous SC infusion</b>	Add to the current doses of midazolam/morphine: <ul style="list-style-type: none"> <li>&gt; either 50mg levomepromazine in the same syringe pump</li> <li>&gt; or phenobarbitone 200–600 mg/day in a second infusion pump.</li> </ul>	
Bolus doses	For levomepromazine, use 12.5–25mg for bolus SC doses For phenobarbitone use 100–200mg for bolus SC doses Nurses to follow plan as detailed above.	
If requiring bolus doses <b>and responding</b>	Re-prescribe the total dose for the previous 24 hours <sup>a</sup> as the baseline CSCI. (The ceiling for levomepromazine is 150mg/24 hrs).	If required, give further bolus SC doses, as needed – usually 20% of infusion rate.
No response	If not responding at this stage, transfer to an IV route is strongly recommended (See Table 5.2c). Note: Stage 3 below may only be used as a holding strategy while IV access and/or transfer to an appropriate setting is arranged. When changing to IV administration, the starting IV dose will usually be the SC regimen at the point of transfer.	
<b>Stage 3 Continuous SC infusion</b>	Continue regimen at current dose in first continuous SC infusion. Start 600–1,200mg/day phenobarbitone in a second CSCI pump. Increase to 2,400mg (and exceptionally above 3,000mg with specialist advice) pending the IVI regime.	
Stage 3 bolus doses	Prescribe phenobarbitone 100–200 mg intramuscular bolus doses or 20% of the infusion rate according to the bolus plan as detailed above.	
If requiring bolus doses	Re-prescribe the total dose for the previous 24 hours* as baseline as CSCI up to maximum dose of 1,200 mg/24 hours.	

<sup>a</sup> If symptom control is not adequate and frequent boluses are required, the baseline infusion should be adjusted more frequently than every 24 hours.

**Table 5.2c Staged escalation of palliative care regimen using IV administration**

<b>Stage 1 continuous IV infusion</b>	<p>Medications are best loaded in separate syringe pumps to start with so that they can be varied independently until the optimum regimen is established.</p> <p>Set up two IVI pumps and commence IV infusion with:</p> <ul style="list-style-type: none"> <li>&gt; midazolam 10 mg/24 hours and</li> <li>&gt; morphine 10 mg/24 hours.</li> </ul>
<b>Bolus doses</b>	<p>Prescribe bolus IV doses of each drug to be given by the syringe pump:</p> <ul style="list-style-type: none"> <li>&gt; 10% of the 24-hour dose for short interventions (eg turning/handling).</li> <li>&gt; 20% of the 24-hour dose for symptom control.</li> </ul> <p>Nursing staff to administer the IV bolus <b>and assess</b> if the achieved desired effect is achieved, which should be evident within 5 minutes.</p> <ul style="list-style-type: none"> <li>&gt; If no response to initial bolus repeat after 5–10 mins</li> <li>&gt; If still no response after two doses, double the bolus dose.</li> <li>&gt; If requiring four or more boluses/hour, increase the background infusion rate.</li> </ul> <p>Medical staff should review the patient at least 3–4 times per day to ensure adequate symptom relief and adjust the infusion dose according to the frequency of bolus doses required up to:</p> <ul style="list-style-type: none"> <li>&gt; midazolam 10–20 mg/hour</li> <li>&gt; morphine 10 mg/hour.</li> </ul> <p>In the large majority of cases, symptoms/signs should be controlled with these two drugs alone, provided that adequate doses are given.</p> <p>However, if no effect is seen from bolus doses, and the patient is receiving the maximum benefit from these drugs, progress to stage 2.</p> <p>Try a test bolus dose of phenobarbitone in the first instance.<sup>a</sup> If a response is observed set up an infusion as per below.</p>
<b>Stage 2 continuous IV infusion</b>	<p>Continue the current doses of morphine and midazolam in one IVI.</p> <p>Set up phenobarbitone 100–200mg in a separate IVI.</p>
<b>Bolus doses</b>	<p>Prescribe bolus IV doses of phenobarbitone 25–50mg.</p> <p>Nurses to follow plan as detailed above.</p> <p>However, if no effect is seen from bolus doses, progress to stage 3.</p>
<b>Stage 3 Continuous IV infusion</b>	<p>Continue morphine at current dose in first continuous IV infusion.</p> <p>Increase phenobarbitone from 600–2,400mg/day in increments in the second IV pump. Exceptionally doses may reach 3,200mg pending self-ventilating anaesthesia with propofol etc as per stage 4.</p>
<b>Bolus doses</b>	<p>Prescribe phenobarbitone IV bolus doses at 20% total daily dose.</p> <p>Nurses to follow bolus plan as detailed above.</p> <p>If not responding to bolus doses, proceed to stage 4.</p>
<b>Stage 4</b>	<p>Self-ventilating anaesthesia.</p> <p>In very rare cases, severe physiological distress with terminal agitation may require self-ventilating IV anaesthesia. This should be administered with the support of ITU-trained staff under the supervision of a consultant anaesthetist.</p>

<sup>a</sup>In transition to stage 2, if phenobarbitone is not immediately available, a bolus dose of levomepromazine 25mg SC may be given as a holding procedure, and repeated if necessary.

## Section 5b Summary of recommendations

Recommendation	Grade
<p><b>5.2.1</b>      <b>End-of-life care for patients with PDOC</b></p> <ul style="list-style-type: none"> <li>&gt; End-of-life care for patients in PDOC following withdrawal of life-sustaining treatment should be organised through closely coordinated specialist neurodisability and palliative care teams.</li> <li>&gt; The setting will depend upon individual circumstances including: <ul style="list-style-type: none"> <li>– the type(s) of life-sustaining treatment withdrawn and the expected mode of death</li> <li>– the experience of the current setting and team,</li> <li>– the likelihood of the complications described above occurring,</li> <li>– access to specialist support and escalation</li> <li>– the wishes of the family and the current care team.</li> </ul> </li> <li>&gt; Sometimes admission to a highly specialist centre will be needed either before starting withdrawal or during the process – especially for patients who are more likely to develop physiological hyperactivity.</li> </ul>	E1/2
<p><b>5.2.2</b>      <b>Care of the dying the patient following withdrawal of CANH</b></p> <p>The elective withdrawal of CANH poses some particular challenges as outlined in Section 5.</p> <ul style="list-style-type: none"> <li>&gt; Even if the patient is not capable of experiencing emotions, feelings or symptoms, behaviours that might indicate distress should be managed proactively to reassure family and care staff that the patient is not suffering.</li> <li>&gt; While the majority of patients may die peacefully without incident, the team should be prepared to manage unpredictable and clinical instability, and palliative care plans must include access to specialist support in case this is required.</li> <li>&gt; Staff should be aware of the particular challenges of managing patients dying from withdrawal of CANH. <ul style="list-style-type: none"> <li>– The dying process can be prolonged – often taking 2–3 weeks, during which the patient will visibly lose weight.</li> <li>– As a result of the physiological and biochemical changes associated with dehydration and catabolism, patients may show signs of ‘physiological hyperactivity’, which may give the appearance that they are aware and experiencing distress.</li> <li>– Even though the patient him/herself may be unaware, this poses a burden of witness for families and staff caring for the patient, and so may be a focus for intervention in its own right.</li> <li>– As most sedative drugs act through modulation of higher cortical function, high doses may be required to achieve the same effect in severe cortical dysfunction.</li> <li>– Appropriate timely escalation is required in a timely manner until a state of ‘calm coma’ is achieved to allow a peaceful and dignified death.</li> </ul> </li> </ul>	E1/2

- Some patients may require IV palliative care regimens and may require management in a specialist centre.

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**5.2.3 Specialist centres for management of elective withdrawal of life-sustaining treatments** **E1/2**

- > Given the challenges for management outlined above, withdrawal of CANH should usually be managed by (or at minimum in liaison with) specialist teams.
- > Such services should be equipped to offer a round-the-clock approach to management, including close collaboration between the specialist palliative care and neurodisability teams.
- > Essential features of the clinical care support that should be available in these specialist centres include:
  - 24-hour dedicated nursing care and on-site medical support to provide competent care of the neurological patient
  - 24-hour access to specialist palliative care support (with anaesthetic backup if required)
  - requisite skills capable for managing the medication regimens set out in Tables 5.2b and 5.2c – including intravenous medication if required
  - access to anaesthetic support for self-ventilating anaesthesia, for the rare occasions when this is necessary
  - specialist support for family, including overnight accommodation.

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**5.2.4 Local management** **E1/2**

In some situations there may be a justifiable preference to keep someone in their locality. In this case, commissioners and senior clinical staff responsible for the patients should ensure that the treating team is fully aware of the challenges listed in 5.2.2 above and has plans to manage them, including access to specialist advice from a clinician with direct experience in this area.

Back-up plans must be in place for urgent transfer to a specialist centre should circumstances require this.

## Section 6

# Service organisation and commissioning

### 6.1 Background and policy framework in England

The *National Service Framework (NSF) for Long-term Neurological Conditions*, published in 2005,<sup>113</sup> emphasised the need for specialist services for people with profound and complex disability. It recommended that rehabilitation services should be planned and delivered through coordinated networks, in which specialist neurorehabilitation services work in both hospital and the community to support local rehabilitation and care support teams. Quality requirement 1 of the NSF specified the requirement for lifelong care with integrated care planning with at least annual review for patients with complex needs.

Since the Health and Social Care Act 2012,<sup>177</sup> responsibility for commissioning of ‘prescribed’ specialised services is the responsibility of NHS England and Improvement (NHSE/I). All other specialist and general services are commissioned at local level by the CCGs.

Under these commissioning arrangements, the NHSE/I service specification D02 (‘Specialised Rehabilitation for Patients with Highly Complex Needs’)<sup>178</sup> includes specialist inpatient assessment, management and rehabilitation of those with highly complex needs, as well as neuropalliative rehabilitation and end-of-life care for patients with profound or total disability (including patients in PDOC).

### 6.2 Organisation of services – a network model

Certain aspects of the management of PDOC require highly skilled specialist trained staff. These include:

- > coordinated assessment and management of highly complex physical, cognitive, sensory and communication disorders
- > medical management including stabilisation of dysautonomia, seizures, complex nutritional needs, decannulation and respiratory management in patients with long term tracheostomies
- > expert assessment and diagnosis of VS and MCS, including the application of formal diagnostics tools, such as the CRS-R, WHIM and SMART
- > organising specialist equipment (eg special seating, electronic assistive technology where appropriate) and the ongoing care and rehabilitation programme
- > *best interests* decision-making, Treatment escalation planning and support for end-of-life care following decisions to withdraw life-sustaining treatment (see [Section 5](#)).

Highly trained rehabilitation professionals are in short supply in the UK, and it is not feasible or economical to duplicate these high-cost / low-volume services in every locality.

To deliver the pathway of care outlined in [Section 3](#), service provision will need to follow a network model with centralisation of key skills in 'specialised' centres, but experienced staff working in both an in-reach and out-reach capacity to support local teams working in other parts of the care pathway.

Within this network model:

- > **Inpatient assessment, rehabilitation and management (phase II):** Experienced multidisciplinary teams in the specialist PDOC neurorehabilitation services provide the highly specialist elements of the pathway, as described above. In England, these tertiary services are commissioned nationally by NHS E/I, through the specialised services framework.
- > **Inreach and outreach support:** The tertiary specialist teams should also provide inreach support to the acute hospitals for specialist advice and outreach support for active management and vigilant assessment in the first year after injury (phase III). After the initial inpatient assessment and management, care will usually be provided closer to the patient's own home. Local inpatient and community rehabilitation services are funded by the local healthcare commissioners (CCG), but the PDOC specialist outreach team will need to provide advisory support to specialist nursing home staff and/or local rehabilitation services.
- > **Community care (phase IV):** Long-term care and support for patients in PDOC is normally provided in a specialist nursing home setting, but occasionally in the patient's own home. This is usually funded through Continuing Health Care budget administered by the local CCGs. Ongoing care needs and eligibility for continuing health funding is reviewed annually by the local CHC team. This should include a review of the Treatment Escalation Plan and discussion with the family about whether continued life-sustaining treatments (including CANH) are in the patient's best interests. The CHC team is responsible for these annual reviews, but they should be informed by an annual review carried out by the PDOC specialist outreach team to:
  - monitor for any significant change in the level of responsiveness or clinical condition
  - confirm a diagnosis of permanent vegetative or minimally conscious state when applicable by an Expert PDOC Physician
  - give advice and support for any *best interests* decisions, including information about prognosis etc.

If elective withdrawal of CANH is considered in a patient who is category 2, 3 or 4 as outlined in [Table 4.2](#), this requires a more detailed process of review, second opinion and *best interests* discussion to complete the documentation described in [Section 4](#). In some cases, this can be a complex and time-consuming process, and depending on the individual circumstances, it may be appropriate to manage this through a brief admission (usually 2–4 weeks) to the specialist PDOC centre. Once these requirements are met and the documentation completed and approved, this may lead on to a terminal care programme (see below) if it is agreed that continued CANH is no longer in the patient's best interests.

- > **Neuropalliative and end-of-life care** for patients in PDOC requires a collaborative approach from both palliative care and neurorehabilitation teams.

- The majority of patients die through naturally occurring intercurrent conditions (eg chest infections etc). End-of-life support under these circumstances should be commissioned locally by the CCGs.
- As noted in [Section 5](#), elective withdrawal of CANH poses some particular challenges and, in some cases, may be best managed in a designated specialist centre. These more complex end-of-life or terminal care programmes should be commissioned centrally by NHS E/I.

### 6.3 Organisation and commissioning of services for assessment and diagnosis

#### Specialist PDOC neurorehabilitation services

Assessment, diagnosis and ongoing monitoring of patients with PDOC should be undertaken by designated specialist PDOC centres. There should be one or more of these in every clinical region, with sufficient capacity to meet demand in order to deliver the requirements set out in these guidelines. They should be led by consultant who meets the criteria for an Expert PDOC Physician and should have a multidisciplinary team of staff that includes senior clinicians who meet the requirements for an Expert PDOC Assessor (see electronic [Annex 2b](#)).

Designated centres are responsible for maintaining appropriately trained specialist staff, experienced in diagnosis and management of patients with PDOC, who are trained in application of the various approved validated tools for assessment and familiar with the information requirements of the minimum dataset.

The designated centre should be responsible for diagnosis, registration and ongoing monitoring of patients with PDOC in conjunction with their local teams.

Assessment/ reviews may be undertaken in the centre or in the patient's home/placement according to patient need. The centre is also responsible for training staff in local centres, eg nursing homes to recognise localising / discriminating behaviours and to use tools such as the CRS-R, WHIM etc to inform monitoring and identify any change in the level of responsiveness that may occur over time.

#### Commissioning arrangements

The expert assessment and management of PDOC is a highly specialised area of healthcare that should be commissioned directly by NHS-E/I.

- > Phase II inpatient assessment and management in designated PDOC centres (including specialised neuropalliative and end-of-life care) already falls under the NHS England 'DO2 Service Specification for Specialist Rehabilitation for Patients with Highly Complex Needs'.<sup>178</sup> This would also include readmission for the purpose of review, second opinion and completion of *best interests* decisions and documentation if elective withdrawal of CANH is considered.
- > Ongoing monitoring of PDOC patients in community settings and support for management and *best interests* decision-making should also be provided from the tertiary specialist centres through outreach services, at least until the patient is diagnosed and registered as being in permanent VS/MCS, and a formal *best interests* discussion has taken place about whether the patient would wish to continue to receive

continued life-sustaining treatment under those circumstances. This is now a legal requirement.

The NHS-E/I commissioning arrangements for these outreach services is not yet established but the Clinical Reference Group for Specialist Rehabilitation has undertaken some preliminary work on outreach tariffs,<sup>179</sup> and a draft service specification has been developed. This is included in electronic Annex 6a.

### Local care arrangements

#### Phase III – active PDOC monitoring

Patients in PDOC are by definition unable to gain from rehabilitation but have complex care needs that require active management, including maintenance therapy and vigilant monitoring usually delivered in a specialist nursing home setting. As such, the expectation is that patients in continuing or chronic VS/MCS should always be the responsibility of the NHS and be considered eligible for non-means tested continuing healthcare funding.

It is recommended that commissioners refer patients for full assessment of eligibility for healthcare funding ('the Decision-making Tool'), *without requirement for an initial checklist*. The threshold for the checklist is set deliberately low to ensure that no one with potentially complex needs is screened out, and provides an additional, unnecessary step in the assessment process for this cohort of patients.

The National framework for continuing healthcare (CHC) and NHS-funded nursing care (FNC), published in 2018/19,<sup>180</sup> makes it explicit that:

- > CHC eligibility assessment should be completed outside of the acute hospital setting to reduce unnecessary delays and to gain a more accurate assessment of need.
- > CCGs should make interim funding arrangements to allow patients to be assessed in their community setting.

However, there are some paradoxes for PDOC patients in this recommendation:

- > CHC assessments that take place in hospital and rehabilitation settings allow input from the specialised team, so that the CHC assessor (who is unlikely to be experienced in the management of patients in PDOC) can understand the nature and complexity of their condition.
- > However, as the patient's needs are usually well managed within a specialised rehabilitation setting, this may mask the true complexity of need that will have to be addressed within a community setting.
- > When the assessment occurs outside of hospital, the CHC assessor is likely to require support from the specialist PDOC team to understand the active management that is still required, the vigilant monitoring and unintended consequences of complex needs not being met (for example non-adherence to 24-hour postural management, the risk of shunt blockage etc).

As noted in Section 3, commissioners and CHC assessors should also be aware that the care package in phase III and IV care must include an appropriate maintenance therapy programme funded by the CCG to manage the patient's ongoing needs, including:

- > physical care – 24-hour positioning and spasticity management, prevention of contractures, tracheostomy management enteral feeding, opportunities for oral feeding etc
- > an appropriate programme of stimulation and opportunities for social activities
- > where necessary, support for communication and interaction. This includes an appropriate wheelchair and seating system, the provision of appropriate communication or environmental control aids and training for care staff to provide opportunities for interaction
- > training for staff to use tools such as the WHIM as a framework to record any observed responses.

### *Completing CHC assessments*

The CHC assessment comprises an assessment of care needs based on 12 domains:

- > behaviour
- > cognition
- > psychological and emotional needs
- > communication
- > mobility
- > nutrition
- > continence
- > skin integrity (including wounds, ulcers, tissue viability)
- > breathing
- > drug therapies and medication: symptom control
- > altered states of consciousness
- > other significant care needs to be taken into consideration.

This assessment forms the basis of the decision for eligibility as the disease or diagnosis is not a determinant on its own. The decision around eligibility is never made with reference to any healthcare costs or healthcare setting.

Patients in PDOC who do not have a tracheostomy or seizures may not trigger a high level of need within many of the 12 care domains. It therefore falls to individual CHC assessor's ability to provide the narrative within the summary of the CHC decision-making tool to support a decision of eligibility.

The tool requires an appraisal of whether the individual has 'a primary healthcare need', and the nature, intensity, complexity and unpredictability of that need.

- > Each of the above characteristics may (either alone or in combination) demonstrate a primary healthcare need because of the quality and or quantity of care that is required.
- > Both the totality of the overall needs, and the interactive effects of the various different needs, should also carefully considered.
- > When making their assessment, CHC assessors should seek out the expertise of the specialised PDOC team and request information on active management, vigilant monitoring, as well as the complexity and unpredictability of day to day care needs.
- > It may be useful consider the 12th domain entitled 'Other significant care needs to be taken into consideration' as the area in which to detail PDOC-specific requirements for supervision and management until a diagnosis of permanence has been made by an Expert PDOC Physician.

### Phase IV long-term care

Once patients are confirmed to be in permanent VS or MCS it is highly improbable that they will emerge into consciousness and the requirement for intensive monitoring will be reduced. At this stage, their needs may simplify, but some patients will still have complex health needs (eg tracheostomy, PEG, need for a postural management programme, seizure management).

Their ongoing qualification for CHC/FNC will need to be reviewed annually. Once there is no need for active vigilance, eligibility for CHC may change, but there is always likely to be a contribution to funding the nursing element of care from local healthcare commissioners (FNC-funded nursing care).

As noted above and in [Section 3](#) the diagnosis of permanent VS/MCS should prompt a further formal discussion with family members present about the patient's likely wishes and whether continued active and life-sustaining treatment is in their best interests. Their Treatment Escalation Plan will also need to be revisited. This should continue to be reviewed annually by the local CCG and care team.

### Home care

As noted in [Section 3](#), patients with PDOC have very intensive and specialist care requirements and it is rarely feasible or practical to provide care in the home setting.

In certain circumstances – in particular where one or more family members are dedicated to providing the role of lead carer – it may be appropriate to provide a home-based support package, which may be provided through NHS CHC budget. Increasingly this is being paid as a personal health budget, so that individuals or family members have more choice over who they can employ.

However, patients with VS and MCS are potentially vulnerable, and such home care arrangements should be subject to risk assessment and adequately supported by a case manager, to ensure that care staff are adequately trained to manage the patients' complex needs. When the care package relies extensively on family members, it is always advisable to make some provision for respite care to enable family members to take a break or attend to alternative commitments, and so avoid carer burnout – or as a back-up plan in case the care package breaks down.

### Phase V end-of-life care

Complex *best interests* decision-making surrounding end-of-life care is again a specialist area of practice.

Decisions to withdraw CANH and other life-sustaining treatments are critical and irreversible. As such they require a carefully documented process of *best interests* discussion and usually a second opinion from a consultant physician expert in PDOC.

Inevitably, these decisions should lead on to an end-of-life terminal care programme. While some patients can be managed satisfactorily with support from the local palliative care team, others pose greater challenges for end-of-life care. In particular, withdrawal of treatments such as insulin, dialysis, tracheostomy or ventilatory support each pose a variety of different considerations requiring an individualised approach to palliative care planning. In some cases,

intravenous medication may be required for the relief of symptoms (see [Section 5](#)) and so necessitate management in a hospital setting with highly specialist experience in this particular area of palliative care (which is not available in most hospices).

These complex elements of care fall under the heading of ‘neuropalliative care programmes’ within the NHSE/I D02 service specification.<sup>178</sup>

### 6.4 Current levels of provision

The GDG recognises that current levels of provision and organisation of services fall considerably short of the recommendations included in this guidance, and do not provide an orderly progression through the care pathway.

The following aspects are identified as particular problems:

- > Due to inadequate bed capacity in the specialist neurorehabilitation centres, some patients are repatriated from acute neurosciences centres or major trauma centres back to their local general district hospital until they can be transferred to an appropriate assessment centre.<sup>110</sup> These local wards typically lack the skills or facilities to evaluate awareness, or to provide the correct postural management to prevent complications such as contractures etc, which can add to the length of stay when they do reach the specialist centre.
- > Special seating is critical to making an accurate diagnosis, but is usually provided through local special seating services who may:
  - refuse to assess the patient until they go home or into a long-term placement or
  - have a slow turnaround for seating provision, and
  - may offer only a limited range of seating options. The timely provision of appropriate specialist seating is essential for this group of patients.
- > Although this guidance places specialist PDOC outreach services at the heart of ongoing monitoring, outreach services are currently in their infancy with only ad hoc funding arrangements in place, creating a major gap in the care pathway. This needs to be addressed as a matter of urgency.
- > There is a paucity of specialist nursing homes in England with the requisite expertise to manage patients in PDOC – especially those with complex needs such as tracheostomy, seizures, dysautonomia etc.
- > Specialised neuropalliative and end-of-life care is also sporadically provided and further development of services is required to be able to deliver this in all parts of the country.

The guidelines therefore make recommendations that cannot be delivered within current resources. However, in the longer term, streamlining of assessment and early direction down appropriate care pathways has some potential to generate cost savings within the acute care services.<sup>110</sup>

### 6.5 Research and development of a national PDOC registry

Further research and development is needed to improve our understanding of PDOC including:

- > the role of functional imaging and electrophysiology
- > longitudinal evaluation of outcomes through cohort analysis to identify:
  - long term prognosis and survival
  - factors that determine prognosis.

- > economic evaluation to identify cost-effective models of care
- > exploration of patient and family perspectives to provide a better understanding of the ethical issues governing *best interests* decisions for life-sustaining treatments
- > data collection on national experience of the clinical process of withdrawal of CANH, to help develop appropriate approaches to palliative care and the optimum regimens to manage end-of-life care within different care settings.

Section 2 recommends the establishment of a national PDOC Registry and agreed minimum dataset for the collection of a national cohort of longitudinal outcome data for patients in PDOC.

The UK Rehabilitation Outcomes Collaborative (UKROC) has established a national database and registry for specialist rehabilitation services that incorporates the inpatient rehabilitation dataset from the NHS Information Centre's Dataset for Long-term Neurological Conditions (LTNC dataset).<sup>181</sup> UKROC currently provides the national commissioning dataset for NHSE/I with permissions in place for patient-level identifiable data to flow to the National Clinical Data Repository for linkage with other clinical datasets. As this represents the only longitudinal database for systematically collating data from patients with complex needs in the UK at the current time, the GDG recommends that the proposed database for PDOC should be incorporated within the UKROC national clinical database.<sup>182</sup> This will require modest investment for database development, and it is envisaged that the (modest) cost of ongoing maintenance will need to be built into commissioning.

## Section 6 Service organisation and commissioning: Summary of recommendations

Recommendation	Grade
<p><b>6.1 Designated specialist services</b></p> <ul style="list-style-type: none"> <li>&gt; Specialist services for the assessment and management of patients in PDOC should be provided in coordinated networks.</li> <li>&gt; Within each network, there should be one or more designated specialist centre for assessment of PDOC with sufficient capacity to meet demand.</li> <li>&gt; Designated centres should have appropriately trained specialist staff who are:               <ul style="list-style-type: none"> <li>– experienced in diagnosis and management of patients with PDOC</li> <li>– trained in the application of the approved validated tools for assessment</li> <li>– familiar with the information requirements of the minimum dataset.</li> </ul> </li> <li>&gt; They should have               <ul style="list-style-type: none"> <li>– at least one senior member of staff who meets the criteria for a specialist PDOC assessor set out in electronic <a href="#">Annex 2b</a></li> <li>– at least two consultant physicians who meet the requirements for an expert in PDOC physician and are registered as such in the National PDOC Registry (when this is developed).</li> </ul> </li> </ul>	<p><b>E1/2</b></p>
<p><b>6.2 Role of the designated services</b></p> <ul style="list-style-type: none"> <li>&gt; The designated centre should be responsible for diagnosis, registration and ongoing monitoring of patients with PDOC in conjunction with their local teams.</li> <li>&gt; Assessment/reviews may be undertaken in the centre or in the patient’s home/placement according to patient circumstances.</li> <li>&gt; The centre is also responsible for training staff in local centres, eg nursing homes to recognise localising/discriminating behaviours and to use.</li> <li>&gt; Readmittance to the specialist centre should be considered if the patient meets the criteria set out in recommendation 6.5 below.</li> </ul>	<p><b>E1/2</b></p>
<p><b>6.3 Commissioning services for specialist assessment and management of patients in PDOC</b></p> <p>The expert assessment and management of PDOC is a highly specialised area of healthcare that should be commissioned directly by NHS-E/I under the national commissioning arrangements for specialised rehabilitation for patients with highly complex needs.</p> <p>The NHS-E/I commissioned services should include:</p> <ul style="list-style-type: none"> <li>&gt; phase II inpatient assessment and management in designated PDOC centres</li> </ul>	<p><b>E1/2</b></p>

Recommendation	Grade
<ul style="list-style-type: none"><li data-bbox="367 224 1292 257">&gt; outreach services to deliver<ul style="list-style-type: none"><li data-bbox="414 257 1292 324">– annual review to monitor any changes in their level of responsiveness until registered as being in permanent VS/MCS</li><li data-bbox="414 324 1292 358">– support for <i>best interests</i> decision-making</li><li data-bbox="414 358 1292 425">– long-term annual follow-up telephone interviews to update the registry.</li></ul></li></ul> <p data-bbox="335 470 1292 591">Complex <i>best interests</i> decision-making and end-of-life care including second opinion and reports for decisions to withdraw CANH and delivery of inpatient terminal care where this is required.</p>	

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**6.4 Funding arrangements for ongoing care** **E1/2**

Patients in continuing or chronic VS/ MCS are by definition unable to gain from rehabilitation but have complex care needs that require active management including maintenance therapy and vigilant monitoring usually delivered in a specialist nursing home setting.

The expectation is that those in VS and MCS should be able to proceed straight to a CHC assessment, without requiring a checklist to be completed, and that they should be deemed eligible for CHC based on the need for ongoing specialist maintenance therapy, monitoring and active vigilance.

Once formally diagnosed and registered as being in permanent VS or MCS, their eligibility for CHC funding may change depending upon their specific healthcare needs, but funded nursing care is always likely to be applicable.

If care is provided in the patient’s home, the care package should include provision for respite care in a suitable specialist nursing home to avoid carer burnout.

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**6.5 National PDOC registry and database** **E1/2**

There should be a National PDOC Registry and an agreed minimum dataset for the collection of a national cohort of longitudinal outcome data for patients in PDOC.

- > All patients who are in VS or MCS at the end of their initial assessment at 3 months post onset/injury should be entered into the register, and reviewed at least annually until either they die or emerge from PDOC.
- > The database should be incorporated within the UK Rehabilitation Outcomes Collaborative (UKROC) national clinical database for specialist rehabilitation.

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**6.6 Elective readmission** **E1/2**

Recommendation	Grade
<p>Following a period of consolidation in the community, a patient may require readmission to formal inpatient neurorehabilitation if any of the following occur:</p> <ul style="list-style-type: none"> <li>&gt; there is improvement of the patient’s level of responsiveness to an extent where he or she would benefit from a specialist goal-orientated rehabilitation programme</li> <li>&gt; the placement proves to be unable to meet the care needs satisfactorily, requiring care needs to be redefined and a suitable alternative found</li> <li>&gt; a specific problem arises that requires admission for disability management (eg severe spasticity, marked postural difficulties, skin pressure ulceration) or medical/surgical management</li> <li>&gt; the patient reaches a critical time point for diagnosis and decision-making and requires a short admission to assess formally the level of awareness and to confirm permanence (or otherwise) (eg for consideration of withdrawal of CANH).</li> </ul>	

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**6.7 Best interests decisions regarding withdrawal of CANH** **E1/2**

From phase III onwards, local health commissioners (ie CCGs) are responsible for ensuring that regular *best interests* discussions take place regarding continuation of life-sustaining treatments, as these should only be given on the basis that they are in the patient’s best interests, taking into account their likely wishes (so far as these can be known).

The annual review should include *best interests* discussions with the family and drawing up/review of any ceiling of treatment plan. These issues should not simply be left to the family to raise (but if the family *do* raise concerns these should be prompt a *best interests* assessment).

The majority of decisions can be made through discussion between the family and treating team. However, in the event of any unresolvable dispute an application to the Court of Protection may be required.

In this case, the commissioners should work with the treating team to identify who will instruct lawyers to prepare the application, but funding for the application will be the responsibility of the service commissioners.

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**6.8 Managing withdrawal of life-sustaining treatment** **E1/2**

While palliative care teams are increasingly becoming familiar with elective withdrawal of CANH for patients in VS, patients in MCS and the withdrawal of other life-sustaining treatments (eg risk of decannulation) is less well understood.

When terminal care plans identify a risk of uncontrolled symptoms, adequate care is usually best provided in (or with support from) specialist units as noted in [Section 5](#).

Recommendation	Grade
<p>Commissioners should ensure that:</p> <ul style="list-style-type: none"><li data-bbox="416 311 1292 378">&gt; adequate commissioning arrangements are in place to support withdrawal of CANH by or in specialist centres</li><li data-bbox="416 383 1292 490">&gt; where local management of withdrawal of treatment can be justified, there is adequate access to specialist advice, and backup arrangements are in place should circumstances change.</li></ul> <p>Local commissioners should therefore be involved in these cases from the earliest possible stage to secure the necessary funding, including emergency escalation plans to move to a specialist centre should this be required.</p>	

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## Appendix 1 Details of methodology

### Evidence gathering

No dedicated funding or resources were available for the assimilation of evidence. It was therefore not possible to undertake full systematic literature evaluation for every aspect of the guideline. Literature searching, review and appraisal was provided by members of the GDG, who were selected for their specialist knowledge and familiarity with the key literature in this area. The RCP Library provided IT support for updated searches, and GDG members were asked to save their search strategies for any literature searches conducted. Date parameters were selected as appropriate to the subject. For example, the term 'vegetative state' was defined in this context in 1972, while minimally conscious state was defined in 2002. Therefore, the search terms limited the data parameters for the search, but otherwise no specific date limits were set.

Evidence was evaluated and assimilated using the typology that was developed to underpin the recommendations in the National Service Framework (NSF) for Long-Term Neurological Conditions.<sup>3</sup> This typology was chosen because it supports the assimilation of a wide range of evidence including quantitative and qualitative research, and professional and user opinion. It is recommended by the RCP when a broad base of evidence is anticipated.<sup>183</sup>

### The NSF typology

Within the typology, each piece of evidence is given an 'R' (Research) or an 'E' (Expert) rating.

### Research evidence

Evidence gathered through formal research processes, is categorised on three levels:

- > design
- > quality
- > applicability.

### Design

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#### Primary research-based evidence

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**P1** Primary research using quantitative approaches

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**P2** Primary research using qualitative approaches

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**P3** Primary research using mixed methods (qualitative and quantitative)

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#### Secondary research-based evidence

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**S1** Meta-analysis of existing data analysis

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**S2** Secondary analysis of existing data.

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#### Review-based evidence

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**R1** Systematic reviews of existing research;

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**R2** Descriptive or summary reviews of existing research

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### Quality assessment

Each quality item is scored as follows: 2 = Yes, 1 = In part, 0 = No

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	<b>Score</b>
Are the research question/aims and design clearly stated?	
Is the research design appropriate for the aims and objectives of the research?	
Are the methods clearly described?	
Is the data adequate to support the authors' interpretations/ conclusions?	
Are the results generalisable?	
Total (High=7–10; Medium=4–6; Low=0–3)	/10

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### Applicability

Applicability to the field of disorders of consciousness:

- > **Direct** – ie evidence from the population of patients with DOC
- > **Indirect** – ie extrapolated evidence from a different population/condition.

Each referenced article is categorised in these three terms. For example, a high-quality study reporting quantitative data from patients with DOC would be categorised '**P1 High Direct**'.

### Expert evidence

Expert evidence is that expressed through consultation or consensus processes rather than formal research designs. It may come from service users (eg families or carers of patients with PDOC) or from professionals. Published expert opinion may come from existing reports, guidelines or consensus statements.

In the absence of formal research or published expert opinion to underpin the guidance, recommendations were developed through an iterative process of drafting and discussing the recommendation statements until consensus was reached within the GDG. In the event of opposing views which could not be resolved through discussion, both viewpoints are presented with their supporting argument to represent the range of opinion.

### Assimilation of evidence to underpin recommendations

Each recommendation has the following ratings according to the strength of supporting evidence:

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Grade of evidence	Criteria
<b>Research evidence</b>	
<b>RA</b>	<ul style="list-style-type: none"><li>&gt; more than one study of high-quality score (<math>\geq 7/10</math>) and</li><li>&gt; at least one of these has direct applicability.</li></ul>
<b>RB</b>	<ul style="list-style-type: none"><li>&gt; one high quality study or</li><li>&gt; more than one medium quality study (4-6/10) and</li><li>&gt; at least one of these has direct applicability</li></ul> or <ul style="list-style-type: none"><li>&gt; more than one study of high-quality score (<math>\geq 7/10</math>) of indirect applicability.</li></ul>
<b>RC</b>	<ul style="list-style-type: none"><li>&gt; one medium quality study (4-6/10) or</li><li>&gt; lower-quality (2-3/10) studies or</li><li>&gt; indirect studies only.</li></ul>
<b>Expert evidence</b>	
<b>E1</b>	User and/or carer opinion
<b>E2</b>	Professional or other stakeholder opinion

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### Meetings and rules of engagement for GDG members

This update to the guidelines was developed over the course of a 9-month period from January to October 2019.

Four all-day meetings of the GDG were held in London, in March, April, July and October 2019.

Meetings were conducted with the full GDG, supported by subgroups to work on line on specific aspects of the guidelines.

GDG members were expected to make a balanced contribution, taking into account the available evidence/range of views in that area, rather than simply adhering to their own individual viewpoint.

Meetings were conducted in confidence.

GDG members were allowed to discuss issues with their multidisciplinary teams in order to seek a balanced view to present to the group. However, they were asked not to share preliminary drafts or other information circulated during the preparation of the guidelines, or to speculate with others about the content/recommendations.

GDG members who represented stakeholder organisations were asked to contact the organisation to confirm their continued representation and to feedback as required during the process. The penultimate draft was circulated to the organisations for their consideration for endorsement.

## Appendix 2

### List of electronic annexes (available online at [www.rcplondon.ac.uk/pdoc](http://www.rcplondon.ac.uk/pdoc))

The following electronic annexes provide additional details and practical tools, and are available online only at [www.rcplondon.ac.uk/pdoc](http://www.rcplondon.ac.uk/pdoc).

<b>Section 1</b>	
<b>1a</b>	Assessing for emergence from a minimally conscious state (MCS)
<b>Section 2</b>	
<b>2a</b>	Full formal clinical assessment of people in prolonged DOC
<b>2b</b>	Minimum requirements experience and training of assessors for patients with a prolonged disorder of consciousness (PDOC)
<b>2c</b>	Optimising conditions for response
<b>2d</b>	A comparison of the WHIM, CRS-R and SMART tools
<b>2e</b>	Checklist of observed responses for families, friends, advocates and care teams to consider
<b>2f</b>	Formal evaluation and record of diagnosis of VS or MCS
<b>2g</b>	Recording forms for interview versions of the WHIM and CRS-R
<b>Section 3</b>	
<b>3a</b>	Clinical management of PDOC patients – an overview
<b>3b</b>	The role of team members working with patients and families in PDOC
<b>3c</b>	Physical management of people with disordered consciousness
<b>3d</b>	Tracheostomy management in patients in PDOC
<b>Section 4</b>	
<b>4a</b>	<i>Best interests</i> checklist for patients in PDOC
<b>4b</b>	Decisions about life-sustaining treatment and people in prolonged disorders of consciousness
<b>4c</b>	Template for Advance Decision to Refuse Treatment
<b>Section 5</b>	
<b>5a</b>	Template for a Treatment Escalation Plan
<b>Section 6</b>	
<b>6a</b>	Draft service specification for outreach services for specialist evaluation and management support for patients in PDOC
<b>6b</b>	Proposed core dataset for a national PDOC registry

## Appendix 3

### Glossary

Acronym	Stands for	Explanation/definition
BSRM	British Society of Rehabilitation	The UK professional society for rehabilitation medicine
ADRT	Advance Decision to Refuse Treatment	A decision made in advance to refuse a specific type of treatment at some time in the future. It must be written down, signed by the individual and witnessed
AGREE	Appraisal of Guidelines for Research and Evaluation	The AGREE Collaboration published standards for the development of clinical guidelines
ANH	Artificial nutrition and hydration	The provision of artificial nutritional and fluid support by means of tube feeding (see under CANH)
BCI	Brain–computer interface	A direct communication pathway between the brain and an external device
CANH	Clinically assisted nutrition and hydration	The provision of nutritional and fluid support by means of ‘tube feeding’ eg given either enterally (via a nasogastric or gastrostomy tube) or parenterally (via an intravenous line)
CCGs	Clinical commissioning groups	NHS organisations that organise and commission the local delivery of NHS services in England
CEEG	Core Executive and Editorial Group	The subgroup of the committee responsible for progressing the draft PDOC guidelines between meetings
CEP	Cognitive evoked potentials	Electrical activity in the brain in response to cognitive stimuli
CHC	Continuing healthcare	A package of care for adults aged 18 or over which is arranged and funded solely by the NHS. For patients with long term health needs
FNC	NHS-funded nursing care	A package of care in which the NHS pays for the nursing care component of nursing home fees
CPR	Cardiopulmonary resuscitation	An emergency lifesaving procedure that is done when someone’s breathing or heartbeat

## Appendix 3 Glossary

Acronym	Stands for	Explanation/definition
		has stopped in an attempt to restore circulation and spontaneous respiration
CSCI	Continuous subcutaneous infusion	A technique whereby fluids are continuously infused into the <b>subcutaneous</b> space via a small-gauge needle
CSR-R	The JFK Coma Recovery Scale – Revised	A 25-item hierarchically arranged clinical assessment scale to evaluate the level of responsiveness in PDOC
CT	Computed tomography	A method of imaging that uses a compute to construct detailed cross-sectional images of various parts of the body from X-rays
DISCs	Depression Intensity Scale Circles	A visual analogue scale designed to facilitate reporting of depression in patients with communication and cognitive deficits
DNACPR	Do No Attempt Cardiopulmonary Resuscitation	A decision made in advance no to attempt CPR in the event of a cardiorespiratory arrest
DTI	Diffusion tensor imaging	An MRI method which supports mapping of the diffusion process of molecules, to allow detailed visualisation of tissue architecture and the neural tracts
EEG	Electroencephalography	A test that records and measures electrical activity in the brain
EOL	End of life	The period towards the end of a person's life when they have a terminal condition and the focus of healthcare is on managing a good-quality death
fMRI	Functional magnetic resonance imaging	A functional neuroimaging procedure that uses MRI technology to measure brain activity by detecting changes in blood flow associated with various cognitive or motor tasks
GCS	Glasgow Coma Scale	A simple clinical assessment scale to evaluate the level of consciousness
GDG	Guideline Development Group	The working party of professionals who developed these guidelines
HDU	High-dependency unit	A ward or department in a hospital where patients are cared for more extensively than on a normal ward
IMCA	Independent Mental Capacity Advocate	A statutory advocate who represents people who lack capacity to make decisions about serious medical treatment and change of accommodation, when they have no family or friends available for consultation about those decisions
ITU	Intensive treatment unit	A special ward or department which provides intensive treatment for very unwell patients; also known as intensive care
IV	Intravenous	A route of administration of drugs or fluid by injection directly into a vein

Acronym	Stands for	Explanation/definition
LPA	Lasting Power of Attorney	A Lasting Power of Attorney is a legal document which allows people aged 18 or above to make appropriate arrangements for family members or trusted friends to be authorised to make decisions on their behalf
MCA	Mental Capacity Act 2005	The act of UK Parliament applying to England and Wales, which provides the current legal framework for acting and making decisions on behalf of adults (16 years old and over) who lack capacity to make particular decisions for themselves.
MCS	Minimally conscious state	A state of wakefulness with minimal awareness characterised by inconsistent, but reproducible, responses above the level of spontaneous reflexive behaviour
MRI	Magnetic resonance imaging	A method of imaging that uses strong magnetic fields and radio waves to produce cross-sectional images of organs and internal structures in the body
NG	Nasogastric	A route of administration where a tube is inserted through the nose and into the stomach – in this context to administer enteral feeding
NHS	National Health Service	A system for publicly funded healthcare systems within the UK, providing health services for residents of the UK
NHSE	NHS England	The national board that oversees commissioning of healthcare services in England and directly commissions specialised services
NICE	National Institute for Health and Care Excellence	A UK body that provides national guidance and advice to improve health and social care
NSF for LTNC	National Service Framework for Long-Term Neurological Conditions	A set of 11 quality requirements, published by the Department of Health in 2005, that sets standards for the care of patients with long-term neurological conditions in England
PAIN-AD	Pain Assessment in Advanced Dementia	An assessment tool for recording pain-related behaviours in patients who cannot communicate their symptoms
PDOC	Prolonged disorders of consciousness	A state of diminished or absent responsiveness/awareness persisting for more than 4 weeks following sudden onset profound acquired brain injury
PEG	Percutaneous endoscopic gastrostomy	A tube inserted through the abdominal wall into the stomach under endoscopic guidance to administer enteral feeding
PET	Positron emission tomography	A nuclear imaging technique that produces a three-dimensional image or picture of

## Appendix 3 Glossary

Acronym	Stands for	Explanation/definition
		functional processes in the body by detecting gamma rays emitted from a radioactive tracer, introduced into the body on a biologically active molecule
PICC	Peripherally inserted central catheter	A form of intravenous access that can be used for a prolonged period of time. A PICC is inserted into a peripheral vein and then advanced through increasingly larger veins, toward the heart until the tip rests in the distal superior vena cava.
RCP	Royal College of Physicians	A professional body which plays a leading role in the delivery of high-quality patient care by setting standards of medical practice and promoting clinical excellence by supporting physicians in over 30 medical specialties with education, training and support throughout their careers
REM	Rapid eye movement (sleep)	A normal stage of sleep characterised by the rapid and random movement of the eyes
SC	Subcutaneous	A route of administration of drugs or fluid by injection under the skin
SDSS	Signs of Depression Scale	A brief screening tool to record behaviours that may be associated with low mood in patients who are unable to report their symptoms
SEP	Sensory evoked potentials	Electrical activity in the brain in response to sensory stimuli
SMART	The Sensory Modality Assessment and Rehabilitation Technique	A detailed clinical assessment and treatment tool developed to detect awareness, functional and communicative capacity in PDOC
SMART-INFORMS	The informal component of the SMART	A questionnaire to obtain information from family and carers regarding observed behaviours and pre-morbid interests, likes and dislikes, as part of the SMART assessment
SPIN	Scale of Pain Intensity	A visual analogue scale designed to facilitate pain reporting for patients with communication and cognitive deficits
SSAM	Sensory Stimulation Assessment Measure	A clinical assessment scale to evaluate the level of responsiveness in PDOC
TEP	Treatment Escalation Plan	Definition
UKROC	UK Rehabilitation Outcomes Collaborative	A programme that holds the national clinical database systematically recording data on needs, inputs and outcomes for all Level 1 and 2 specialist rehabilitation services in England
UWS	Unresponsive wakefulness syndrome	A term used by the European Task Force on Disorders of Consciousness to replace 'vegetative state'

## Prolonged disorders of consciousness

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<b>Acronym</b>	<b>Stands for</b>	<b>Explanation/definition</b>
VS	Vegetative state	A state of wakefulness with absent awareness, characterised by complete absence of behavioural evidence for self- or environmental awareness
Welfare LPA	The donee of a 'Health and Welfare Lasting Power of person Attorney'	A named individual appointed through an LPA to make decisions about health and welfare on behalf of someone else when him/himself no longer has capacity
WHIM	The Wessex Head Injury Matrix	A clinical assessment scale consisting of a 62-item hierarchical scale to monitor an individual's level of responsiveness and interaction with their environment following brain injury
WNSSP	Western Neuro Sensory responsiveness in Stimulation Profile	A clinical assessment to evaluate the level of PDOC

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**ISBN 978-1-86016-793-5**  
**eISBN 978-1-86016-794-2**

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