

# Patients in a Prolonged Disorder of Consciousness: diagnosis & management

A one-day seminar.

## Overview.

This seminar will cover all aspects of diagnosis and management, specifically considering the recent BMA/RCP guidance, the Mental Capacity Act 2005, determining a person's best interests and end-of-life care associated with withdrawal of nutrition and hydration, but also considering broader aspects such as the effects upon the family and ethical concerns. It has been allocated six Continuing Professional Development points.

## Time, place, application

The seminar will be on **Wednesday 24th April 2019**, running from 09.00 to 17.00. It will be at the **Headington Campus** (Gypsy Lane site; OX3 0BP) of Oxford Brookes University (<https://www.brookes.ac.uk/about-brookes/contacts-maps-and-campuses/headington-campus/>) There is no parking. Park and Ride buses (Thornhill or Seacourt sites) stop outside.

The cost is £100, and an **application** to participate can be made online:

<https://www.eventbrite.co.uk/e/prolonged-disorders-of-consciousness-clinical-decision-making-tickets-50435521001>.

## Contributors.

There are five experts contributing. All have been involved, directly or indirectly, with the new guidance published by the British Medical Association and Royal College of Physicians and endorsed by the General Medical Council.

- Professor **Lynne Turner Stokes** was the initiator and chair of the working party that produced the National Clinical Guideline on managing people with a prolonged disorder of consciousness in 2013. She has been involved in assessing patients for the Court of Protection for many years, and has been in some leading cases. She was the Royal College of Physicians representative on the multi-organisational working party, run by the BMA, which developed the new clinical guidance.
- Professors **Jenny and Celia Kitzinger** have been involved in many aspects of the management of people with prolonged disorders of consciousness since their sister, Polly was injured in an accident in 2009. They have undertaken extensive research into clinical, ethical, legal, and family aspects of patients with a prolonged disorder of consciousness. (see <http://cdoc.org.uk/>) They have produced a major online resource for families. (<http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/overview>). Celia was on the BMA working party with Lynne.
- Dr **Andrew Hanrahan** has had a close interest since his training in rehabilitation when he wrote a dissertation on the ethical and legal aspect for King's College, London. He is now Lead Clinician for brain injury services at the Royal Hospital for Neurodisability, Putney which has for many years been the foremost hospital for assessing and managing

patients with a prolonged disorder of consciousness. He is also clinically involved with many patients, including many assessments for the Court of Protection. He participated in the public consultation about the new guideline.

- Professor **Derick Wade** has been involved in assisting the Court of Protection with these cases since 1995, and has been involved in giving second clinical opinions outside a medico-legal process on many occasions. He has written extensively about different aspects of the assessment and management of people with a prolonged disorder of consciousness. He also participated in the public consultation about the new guideline.

### **Who this is for, and preparatory reading.**

It is anticipated that people attending will already have had some involvement in the management (including legal aspects) of patients with a prolonged disorder of consciousness, and thus have sufficient clinical exposure to know what they need to know. Those attending may be from any profession, though it is likely that **doctors** will predominate; **lawyers and others** are also welcome. Those attending may be from any medical speciality, but will probably be from one of intensive care, neurology and neurosurgery, rehabilitation, care of the elderly, and palliative care. They are likely to have been qualified for at least 5 years.

In order to optimise participation, each person enrolled will be given a list of relevant reading materials. It is **not** anticipated that each document will be fully read and learned! It is anticipated that each will have been looked at, and a few read in detail; they may well be discussed by the experts in the discussion. A list of documents and other resources is given at the end, which also indicates which are openly available.

### **Structure and content.**

The seminar will be restricted to sixty people attending, because its structure and style will be one of open discussion between the experts and the people attending - and also both between the experts themselves and between those attending themselves.

The overall structure is to have four major sessions (two in the morning, two in the afternoon) focussed on general areas (see below), with a relatively short introduction to the area for discussion. It is anticipated that in each session, matters well outside the specific topic will be discussed and this discussion will not be curtailed, provided the central topic is covered.

The four major session topics will be:

- **neurological matters.** This will cover causation, assessment both neurological and of awareness, and investigations. It will present a structured way to approach the patient. It will outline the evidence, especially in relation to the assertion of a "40% misdiagnosis rate". It will emphasise the need to accept and acknowledge uncertainty but will also

show that most uncertainty is minor and usually of no actual importance.

- **prognosis, and treatments.** This will cover the related issues of interventions to optimise recovery of awareness, including active reduction and withdrawal of sedating treatments, and the natural history of prognosis after brain injury. Its scope is limited to matters that have direct relevance to the best interests decisions, and it will not cover general management - which is covered extensively in the National Clinical Guideline.
- **family, and patient wishes.** This will cover both the impact upon families, and their experience and perspective on usual management, and the role of families in the decision-making process. In terms of establishing the patient's likely wishes - the main focus - the need to differentiate family wishes from patient wishes, and the need to seek out information from many sources including social media and friends will both be emphasised with practical advice on how to achieve it.
- **the decision-making process.** This will consider aspects of making best interest decisions. Though this will concentrate upon (a) decisions on feeding and hydration and (b) people who lack full awareness, the principles will apply to all adults lacking mental capacity and to all decisions, and so it will be relevant to much clinical practice. It will specifically discuss matters such as when and how to obtain a second clinical opinion - and how to give a second opinion.

Each session will be about one and a half hours long, with a short (maximum 30 minutes) initial more formal presentation of key information. There may follow a short additional comment by the other experts (to break the ice) and then the topic will be open for general questioning and discussion. At the end of the session, there will be a brief resumé before a break and then the next session. An outline schedule is given on the next page.

### **Learning outcomes.**

At the end of the day's seminar, those attending will have the following capabilities relating to the diagnosis and management of people lacking the mental capacity to make a decision about their healthcare due to a prolonged disorder of consciousness. They will be able to:

- comply with and explain the current legal position concerning both not providing and withdrawing active life-sustaining treatments for people;
- explain to families and team members the neurological diagnosis (what and where) of the patient, and how it accounts for and relates to the clinical state;
- determine the level of awareness and responsiveness of a patient, and explain this to families and team members including giving the range of uncertainty;
- be able to give a prognosis to families and team members, in terms that are relevant and understandable;
- comply with the requirements of the Mental Capacity Act 2005 in relation to making decisions in the person's best interests, and knowing practically how to achieve this;

- be able to support families appropriately in terms of emotion, information and practical advice, on the basis of a clear appreciation of their perspectives;
- acknowledge and manage the many areas of uncertainty and doubt in a consistent way.

**Seminar schedule**

<b>Time</b>	<b>Topic</b>	<b>Comment</b>
08.45 - 09.15	Registration, coffee etc	
09.15 - 10.45	Neurological diagnosis and assessment of awareness  Dr Wade lead	This will cover establishing the nature and extent of both the neurological damage and the level and variability in awareness, and how the level of (un)certainity is established and minimised. The role of specific assessments (e.g. CRS-R and fMRI) will be discussed.
10.45 - 11.15	Coffee break and discussion	<i>It is anticipated that coffee may be in the same room, encouraging ongoing discussion and questioning</i>
11.15 - 12.45	Treatments and prognosis  Dr Hanrahan lead	This will cover potential treatments both to increase awareness (e.g. amantadine, zolpidem) and to sustain life or treat complications (e.g. ventilation, shunt insertion, gastrostomy), and how to establish and discuss prognosis.
12.45 - 13.30	Lunch (and discussion)	<i>Also in the same room (perhaps discussion should be banned for 45 minutes!)</i>
13.30 - 15.00	Establishing patient wishes and experiences  Profs Celia and Jenny Kitzinger lead	This will cover what needs to be established about the patient's views and how to achieve this. It will also discuss how one might establish the patient's experience of their situation. Matters such as advance decisions, and deputies will be discussed.
15.00 - 15.30	Tea break and discussion	<i>It is anticipated that tea may be in the same room, encouraging ongoing discussion and questioning</i>
15.30 - 17.00	Deciding best interests  Dr Turner Stokes lead	This will discuss the nature of best interests, how to raise and consider decisions that might reduce the chances of survival, and how to make decisions. It will particularly set the meeting in the context of an ongoing process of reviewing best interests over time

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**Reading materials.**

The following documents are relevant. Those freely available already are indicated with an asterisk and should be downloaded by the person attending. Anyone registered with NHS Athens should be able to download/access the remaining papers.

- \* The National Clinical Guideline. <https://www.rcplondon.ac.uk/guidelines-policy/prolonged-disorders-consciousness-national-clinical-guidelines>
- \* Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent. Guidance for decision-making in England and Wales. <https://www.bma.org.uk/advice/employment/ethics/mental-capacity/clinically-assisted-nutrition-and-hydration>
- How many patients in a prolonged disorder of consciousness might need a best interests meeting about starting or continuing gastrostomy feeding? <https://doi.org/10.1177/0269215518777285>
- How often is the diagnosis of the permanent vegetative state incorrect? A review of the evidence. <https://doi.org/10.1111/ene.13572>
- Using best interests meetings for people in a prolonged disorder of consciousness to improve clinical and ethical management. <https://doi.org/10.1136/medethics-2017-104244>
- Back to the bedside? Making clinical decisions in patients with prolonged unconsciousness. <http://dx.doi.org/10.1136/medethics-2015-103045>
- \* An NHS Trust and others (Respondents) v Y (by his litigation friend, the Official Solicitor) and another (Appellants). <https://www.supremecourt.uk/cases/docs/uksc-2017-0202-judgment.pdf>
- \* Mental Capacity Act 2005. Code of Practice [http://www.direct.gov.uk/prod\\_consum\\_dg/groups/dg\\_digitalassets/@dg/@en/@disabed/documents/digitalasset/dg\\_186484.pdf](http://www.direct.gov.uk/prod_consum_dg/groups/dg_digitalassets/@dg/@en/@disabed/documents/digitalasset/dg_186484.pdf)  
<http://www.publicguardian.gov.sg/Portals/0/Guides/COP%20guide.pdf>
- \* Treatment and care towards the end of life: good practice in decision making. <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life>
- \* Deaths after feeding-tube withdrawal from patients in vegetative and minimally conscious states: A qualitative study of family experience. <http://journals.sagepub.com/doi/full/10.1177/0269216318766430>

- \* Why futile and unwanted life-prolonging treatment continues for some patients in permanent vegetative states (and what to do about it): case study, context and policy recommendations.  
<http://www.northumbriajournals.co.uk/index.php/IJMHMCL/article/view/687/1073>
- \* Dying well with reduced agency: a scoping review and thematic synthesis of the decision-making process in dementia, traumatic brain injury and frailty.  
<https://bmcmedethics.biomedcentral.com/articles/10.1186/s12910-016-0129-x>
- \* Mental capacity and best interests decisions - a guide for healthcare practitioners.  
<http://cdoc.org.uk/wp-content/uploads/2014/05/Best-Interests-Booklet-Wade-HighRezJuly2017.pdf>
- Clinically assisted nutrition and hydration. Landmark decision returns decision making to clinical teams and families. <https://doi.org/10.1136/bmj.k3869>
- \* Families' experiences. <http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/overview>