

# Conscientious care for the unconscious patient: new guidance from the Royal College of Physicians

Author: Derick Wade<sup>A</sup>

ABSTRACT

**Patients who remain unconscious and unaware after a brain insult challenge healthcare. Clinicians are faced with a clinical situation often outside their usual experience. Organisations are faced with practical issues concerning resource use. And people, especially family and friends, are faced with moral, legal and philosophical questions that have no easy answers. This conference launched national guidelines that should assist clinical teams and organisations, and should ensure that all patients and families receive a good quality service.**

**KEYWORDS:** Unconscious patient, brain insult, national guidelines

A report on a conference held at the Royal College of Physicians (RCP) on 12 December 2013 to launch the new *Prolonged disorders of consciousness: national clinical guidelines*.

## Introduction

Most people who become comatose as part of a medical illness regain consciousness, and most recover good if not normal function. Unfortunately a small proportion remain unconscious for weeks after onset, and a very small proportion remain unconscious and unaware for over 1 year – they are in the permanent vegetative state (PVS).

These patients may start their illness in any medical (including surgical) specialty, and the clinical team usually has little or no experience of this problem. Until recently no specialty or service could, or would, take over the necessary specialist management and many patients, and their families, received a patchy, often poor, clinical service. Over the last 10–20 years a few neurological rehabilitation services have built up expertise and services.

## Guideline: scope and process

In late 2010 a working party was set up to review and revise the existing 2003 RCP guideline on the permanent vegetative state. This group agreed that a more comprehensive guideline was needed to cover both a broader range of states (eg minimally conscious state) and the whole pathway. The resultant

document, *Prolonged disorders of consciousness: national clinical guideline*,<sup>1</sup> was launched at a conference on 12 December 2013.

The central message is that clinical teams managing patients who have been left unconscious should use a patient-centred approach, based on a holistic evaluation of the situation, as should be the case for all their patients. The guidance emphasises that the Mental Capacity Act 2005 can be used to help clinical teams in the process. The conference covered some of the many issues raised by this clinical situation.

## Families

Two of the ten speakers were family members of patients. This unusual feature reflects the fact that the patients are unable to interact and families both expect and are expected to take a much greater part in making decisions. This strain adds to the already large stresses associated with the patient's illness: uncertainty about outcome, practical problems, emotional responses, not getting information on or understanding the clinical situation, etc. The guideline itself also has about 20% of its content focused especially on families.

There was a riveting talk by Helen Steeple, mother of a patient who had a major brain injury in a road traffic accident – for 30 minutes there was silence, and at the end most people were crying silently. She catalogued a series of failures in providing basic care within the National Health Service (NHS) that should shame us all; but worse still she reported calmly on the lack of knowledge and skills in the care teams and an attitude that was not empathetic. She then described the nightmare journey through the legal process of gaining permission to stop clinically assisted nutrition and hydration culminating, worst of all, in the care staff reporting signs of awareness that were not there.

Professor Jenny Kitzinger is the sister of another patient who sustained severe brain damage passing through the vegetative state. She presented another, much bigger and equally concerning set of data gathered from 51 family members with experience of having a relative in the vegetative or minimally conscious state. The data showed:

- > serious lack of knowledge about basic laws governing clinical care set out in the Mental Capacity Act 2005, especially on how to determine and then act in the patient's best interests
- > repeated and serious failures to communicate with families
- > failures in human empathy and understanding.

These two talks emphasised the urgent need for all doctors and other care staff to treat patients with serious brain injury

**Author:** <sup>A</sup>consultant and professor in neurological rehabilitation, Oxford Centre for Enablement, Oxford, UK

and prolonged disorders of consciousness with the knowledge, skills and respect that they deserve. Currently the NHS fails this group of patients.

## Lawyers

Two of the ten speakers were lawyers. Again, this unusual feature reflects the central role of law (and ethics) in the management of unconscious patients. All medical treatment requires the consent of the patient. No one else can give consent, not even relatives.

The two lawyers, Yogi Amin and Barbara Dolan, discussed the Mental Capacity Act 2005, its meaning and its implementation. The important facts are:

- > to recognise that any and all treatment of a patient without capacity must always be in the best interests of the patient
- > that for any significant decisions, this requires a formal meeting to discuss best interests
- > that the concept of best interests is large and not simply confined to the preservation and prolongation of life
- > to use a formal process to arrive at decisions that are in the patient's best interests.

There was then some discussion on the role of the Court of Protection, which at present must be consulted if considering withdrawing clinically-assisted nutrition and hydration (CANH) and should be consulted in other cases of significant doubt or dispute. Detailed guidance on all the legal issues can be found in the guideline.

## Ethical issues

Although there was no formal session on ethics, nevertheless two ethically charged issues were discussed. The first, unresolved issue was a perception that good clinical practice, indeed legally required clinical practice such as holding best interest meetings and acting on the decisions made, would probably require resources that were not available. Other examples included the recommendations for involving specialist teams and meeting the costs of legal cases going to the Court of Protection.

The Mental Capacity Act is a law, and the NHS has to comply with the law, so there is no option. Moreover it is arguable that high-quality care and regular best interests meetings might actually reduce costs.

The second issue, unsurprisingly, concerned one particular recommendation and its consequences.

The guideline reminds clinicians about the law, and recommends that a formal best interests meeting should be held once it is obvious that a patient is in a PVS and that this meeting should formally discuss whether CANH remains in the best interests of the patient. In the many cases taken to court, it has been agreed that a patient in the vegetative state gains no benefit from CANH and so treatment should not be continued because it is futile. Thus the best interests meeting should start from the premise that CANH is no longer an appropriate treatment.

The logic is firm; we shall see if this recommendation is followed through.

## Diagnosis and terminology

The issue of diagnosing and naming states remains contentious, primarily because these are emotive matters.

The UK will probably continue to use the 'vegetative state' as the diagnostic label for someone who has a sleep-wake cycle (ie no longer strictly in a coma) but who is otherwise unaware of him- or herself or his or her environment, and to use 'minimally conscious state' as the diagnostic label for someone who is aware, but only intermittently and/or at a very basic level.

There is widespread concern about the term 'vegetative', but it has the advantage of being widely used and short; moreover, although some people dislike it, there are relatives and others who prefer it to one of the many alternatives. The term 'minimally conscious' is less contentious and is used in preference to 'minimally aware' simply to encourage consistency with worldwide terminology.

The guideline gives 'generally accepted criteria' for diagnosing awareness, and also for identifying the even more difficult distinction between minimal consciousness and simply being severely impaired secondary to brain damage.

There are no independent criteria for determining awareness, which is scarcely surprising given the continuing philosophical and scientific debates about the nature of consciousness itself. However, clinical criteria are still the bedrock for establishing whether or not someone is aware. The undoubtedly interesting evidence from current studies of cerebral function in people with prolonged disorders of consciousness remains clinically unhelpful.

## Management

The guideline has much specific guidance on how to manage this group of patients. The recommendations can be summarised as follows:

- > Involve a specialist clinical neurological rehabilitation service as soon as possible.
- > Ensure accurate diagnosis of the state of awareness as soon as possible and monitor it over time.
- > Provide high-quality care with active involvement of families from the outset, following guidance given in many other national documents on neurological rehabilitation.

Two issues relating to the UK are worth noting: first it is recommended that national specialist commissioning should fund all active healthcare and that continuing healthcare funding should be responsible for all long-term care costs in specialist nursing homes or elsewhere, while someone is in a vegetative or minimally conscious state. Second, the standards recommended should also apply to all other people with prolonged neurological losses, not simply people who happen to fall within the scope of this guidance. ■

## References

- 1 Royal College of Physicians. *Prolonged disorders of consciousness National clinical guidelines*. Report of a working party 2013. London: RCP, 2013. [www.rcplondon.ac.uk/resources/prolonged-disorders-consciousness-national-clinical-guidelines](http://www.rcplondon.ac.uk/resources/prolonged-disorders-consciousness-national-clinical-guidelines) [Accessed 12 March 2014].

**Address for correspondence: Dr D Wade, Oxford Centre for Enablement, Windmill Road, Oxford OX3 7HE.  
Email: [derick.wade@ouh.nhs.uk](mailto:derick.wade@ouh.nhs.uk)**