

## Prolonged disorders of consciousness: new national clinical guidelines from the Royal College of Physicians, London

**Author:** Lynne Turner-Stokes<sup>A</sup>

Patients who remain in a prolonged disorder of consciousness 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.

By definition, these patients lack the mental capacity to make decisions regarding their own care and treatment, so such decisions have to be made for them on the basis of their best interests. Exactly where those interests lie, however, 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 best 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, but in some instances they may require judgement from the court.

On 12 December 2013, the Royal College of Physicians (RCP) launched its new national clinical guidelines for prolonged disorders of consciousness (PDOC). The new guidelines update and replace the 2003 RCP report *The Vegetative State*,<sup>1</sup> aiming to achieve a more consistent approach to diagnosis and management of patients with PDOC, including vegetative (VS) and minimally conscious states (MCS).

Since the 2003 RCP report was published, there have been changes in practice for diagnosis and management, based on new research and legislation. In 2005, the Mental Capacity Act introduced a new legal framework for clinical best interests decision-making,<sup>2</sup> and more recently the Health and Social Care Act 2012 introduced major changes to the way that health and social care services are commissioned and administered in England.<sup>3</sup> In addition, there was a need for more clarity on the complex medical, legal and ethical issues involved in caring for these patients and supporting their families.

Key aims of this new set of guidelines are to:

- improve the diagnosis and management of patients in VS and MCS, and to improve understanding of the medical, legal, and ethical issues surrounding their care
- provide practical and useful advice for clinicians who work with this group of patients
- set out best practice within the existing legal framework for clinicians, commissioners and service providers
- help clinicians to provide better information for patients' relatives, friends, carers and representatives, and to involve them appropriately in decision-making regarding care and treatment, as required by the Mental Capacity Act 2005.

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 (GDG) was a multidisciplinary group representing clinicians who work regularly with patients in PDOC from a range of different medical and health professions, commissioners, advocacy services, legal professionals and patient/family representatives. The 29 GDG members were deliberately chosen to represent a wide range of opinion. Some of the topics addressed by the group provoked rigorous and prolonged discussion, but we have endeavoured to provide a balanced view, based on the best evidence available at the current time.

No dedicated funding or resources were available for the assimilation of evidence, but systematic literature searching, review and appraisal were conducted in key areas by members of the GDG, who were also selected for their specialist knowledge and familiarity with the literature in this field. 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>4</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>5</sup>

The guidelines do not seek in any sense to challenge existing law, but we have attempted to lay out for clinicians, service providers and commissioners what constitutes best practice within the existing legal framework, to enable them to fulfill their various responsibilities to the patient and their family.

**Author:** <sup>A</sup>Herbert Dunhill professor of rehabilitation, Department of Palliative Care, Policy and Rehabilitation, King's College London, UK

The guidelines are divided into six sections:

- 1 Definitions and criteria for diagnosis of vegetative and minimally conscious states
- 2 Assessment, diagnosis and monitoring
- 3 The care pathway from acute to longer-term management
- 4 Ethical and medico-legal issues
- 5 End-of-life decisions and care
- 6 Service organisation and commissioning.

Each section ends with a set of specific recommendations with evidence grading. Although these are written for the specific legal and cultural context of the English health system, many of the principles and approaches will have application in other jurisdictions – both in the UK and further afield.

In addition to the main document, there are a number of electronic annexes available for free download from the website ([www.rcplondon.ac.uk/resources/prolonged-disorders-consciousness-national-clinical-guidelines](http://www.rcplondon.ac.uk/resources/prolonged-disorders-consciousness-national-clinical-guidelines)), which provide tools and more specific advice to assist clinicians in the management of patients with PDOC at the ‘coal face’ of clinical practice.

In this rapidly changing field the recommendations are likely to need updating as new evidence emerges and as international consensus develops. Further systematic longitudinal data collection is urgently required in this area and the GDG has recommended the development of a national register and dataset to facilitate this – a recommendation that is strongly endorsed by

the RCP Council. In the meantime, the new guidelines provide a practical source of advice for clinicians who work with this complex and challenging group of patients.

## References

- 1 Royal College of Physicians. The vegetative state: guidance on diagnosis and management. London: RCP, 2003. [www.rcplondon.ac.uk/sites/default/files/documents/vegetative-state.pdf](http://www.rcplondon.ac.uk/sites/default/files/documents/vegetative-state.pdf) [Accessed 4 December 2013].
- 2 Her Majesty's Stationery Office. *The Mental Capacity Act 2005*. London: HMSO, 2005. [www.legislation.gov.uk/ukpga/2005/9/contents](http://www.legislation.gov.uk/ukpga/2005/9/contents) [Accessed 4 December 2013].
- 3 The Stationery Office. *Health and Social Care Act 2012*. London: The Stationary Office, 2012. [www.legislation.gov.uk/ukpga/2012/7/pdfs/ukpga\\_20120007\\_en.pdf](http://www.legislation.gov.uk/ukpga/2012/7/pdfs/ukpga_20120007_en.pdf) [Accessed 4 December 2013].
- 4 Turner-Stokes L, Harding R, Sergeant J *et al*. Generating the evidence base for the National Service Framework for Long Term Conditions: a new research typology. *Clin Med* 2006;6:91–7.
- 5 Baker A, Potter , Young K, Madan I. Grading systems and critical appraisal tools: a study of their usefulness to specialist societies. *Clin Med* 2010;10:358–63.

**Address for correspondence: Prof L Turner-Stokes, Department of Palliative Care, Policy and Rehabilitation, King's College, Cicely Saunders Institute, Bessemer Road, London SE5 9PJ. Email: [lynn.turner-stokes@dial.pipex.com](mailto:lynn.turner-stokes@dial.pipex.com)**

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