

## **Prolonged Disorders of Consciousness Task and Finish Group – Final Report**

### **Background**

1. Relevant guidance<sup>1</sup> regarding prolonged disorders of consciousness has been well established since 2013. However, determining the number of patients in these conditions across Wales is not easy to clarify.
2. The legal position regarding the withdrawal of clinically assisted nutrition and hydration (CANH) was clarified via a Supreme Court Decision in July 2018. The court ruled that judicial approval will no longer be required before discontinuing life-prolonging treatment for individuals with a prolonged disorder of consciousness (PDOC), which includes both a permanent vegetative state (PVS) and a minimally conscious state (MCS), provided that there is agreement upon what is in the best interests of the patient, the provisions of the Mental Capacity Act 2005 have been followed, and the relevant professional guidance has been observed.<sup>2</sup>
3. In January 2018, the Cabinet Secretary for Health and Social Services issued a written statement stating he is keen for lessons to be learnt from the experiences of Welsh patients and their families relating to the treatment of prolonged disorders of consciousness.
4. The Cabinet Secretary asked the Deputy Chief Medical Officer for Wales to convene a task and finish group to consider the need for any additional guidance, education or training to be developed for the health and social care sector in Wales.

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<sup>1</sup> <https://www.rcplondon.ac.uk/guidelines-policy/prolonged-disorders-consciousness-national-clinical-guidelines>

<sup>2</sup> *An NHS Trust v Y* [2018] UKSC 46.

5. Health professionals within both the multi disciplinary and wider care teams aim to provide the highest level of care in the best interests of their patients. It is a well-established legal principle that CANH is a form of medical treatment. It follows that, like all other forms of medical treatment, it can only be provided to patients who lack capacity when it is in their best interests. There is a strong presumption that it will be in the patient's best interests to receive treatment that will keep them alive, but for some patients this will not be the case as it will not provide them with a quality of life that they would find acceptable. For this reason, it is essential that all decisions about CANH follow careful consideration of the individual circumstances of the patient. The impact of making the "wrong" decision for the individual can be grave – either withdrawing CANH too soon, thus depriving the individual of a chance to live a life they would have wanted, or providing it contrary to a patients' best interests, potentially for a very long period of time. It is therefore important for all parties concerned to be aware of the legal implications and to understand the guidance relating to decision making.
  
6. In relation to guidance for health care professionals, joint interim guidance<sup>3</sup> relating to decisions not to continue clinically-assisted nutrition and hydration was produced in 2017 by the General Medical Council (GMC), British Medical Association (BMA) and Royal College of Physicians (RCP). The BMA has recently completed work on substantive professional guidance which will be published jointly with the Royal College of Physicians (and endorsed by the GMC) at the end of November 2018. This will be available at [www.bma.org.uk/CANH](http://www.bma.org.uk/CANH). This should be read alongside the RCP clinical guidance for Prolonged disorders of consciousness.<sup>4</sup>
  
7. In 2017, the Chief Medical Officer wrote to health board medical directors to seek assurance that the diagnosis, treatment, care and related decision making

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<sup>3</sup> <https://www.gmc-uk.org/-/media/ethical-guidance/related-pdf-items/end-of-life-care/making-decisions-to-withdraw-canh-from-patients-in-pvs-and-mcs.pdf>

<sup>4</sup> <https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&ved=2ahUKewisqpnWv5zeAhUPylUKHQc7AH8QFjABegQIBxAC&url=https%3A%2F%2Fwww.rcplondon.ac.uk%2Ffile%2F4050%2Fdownload%3Fto-ken%3DvXQIJzgz&usg=AOvVaw07iDBPQ-PtJH8Qwvvp089Lw>

for patients in these conditions is being undertaken in line with legal requirements and national guidance.

8. The result of this work highlighted difficulties accurately capturing the number of patients in this condition and issues relating to providing a clear diagnosis.
9. A task and finish group was created and tasked with considering how to improve all services along the pathway for all those affected by prolonged disorder of consciousness. This includes a requirement to consider the care pathway and process from beginning to end.
10. This report sets out the current issues facing professionals and patients, as well as proposing potential approaches and requirements to improve services including providing information for patients and healthcare professionals.

### **Task and Finish Group**

11. The group consisted of a wide range of expertise with the ability to provide a high level overview of current services. The initial task of the group was to explore the historical issues, reflect on the current system and consider future service requirements in Wales.
12. To aid the understanding and work of the group, expert testimonies, patient stories and advice from advocates were provided. The group considered the practicalities required to improve services across Wales and the wider range of issues.
13. The group deliberated whether children should be considered within the scope of this work and concluded their recommendations should be focussed on prolonged disorders of consciousness in adults. However the key principles can be applied as the issues displayed are similar. PDOC specialists in Wales treat adults over 18 and in specific circumstances can look after those over 16.

## Summary of key issues

14. The group found a number of reoccurring key issues and reviewed numerous areas where amendments or development could help improve services and treatment.

### Identifying patients / Existing cases

15. To improve services, understanding of the current status of patients and provisions within Wales is required. Patient care is provided within a number of settings, including hospital wards, community settings, care homes and their own homes. This makes identifying the numbers of patients in a prolonged disorder of consciousness difficult.
16. An exercise undertaken by the Welsh Government sought to identify the number of patients in this condition, but unfortunately did not yield conclusive responses. A multi-organisational approach is likely to yield better results. To better understand the number of patients affected, it would be necessary to consider historical legal cases, continuing healthcare packages, work undertaken by specialist dieticians, information from specialist nursing homes and utilising the knowledge of colleagues in specialist centres. The use of data held in registries may also be helpful, such as the Trauma Audit and Research Network (TARN), Intensive Care National Audit and Research Centre (ICNARC) and primary care registers.
17. Although a resource intensive exercise, it is important to ensure the scale of the issue is known and understood and any guidance developed for existing cases is provided to staff and families who require it. This would require coordination from an NHS body.
18. We recommend further exploratory work and consideration be given to whether Wales would benefit from a register or an audit of patients in these conditions. A register would require logistical support.

## Family Support

19. The national clinical guidelines for PDOC (2013) published by the RCP outlines the critical need to provide information and support to families<sup>5</sup> and/or other people with strong emotional attachments to the patient in order to provide high quality care. The guidelines indicate that this may encompass information about the patient's clinical state, prognosis, treatment options and proposed management plan; emotional and practical support. Families will likely vary in their readiness to receive information/support and to engage in difficult discussions with those looking after the patient, therefore professionals need to be aware of this and respond according to the needs of the family. The approach taken towards families should not be standardised but rather tailored towards the needs/circumstances of the patient and their family. Discussions regarding care will vary and numerous factors require consideration, including cultural, religious and personal held beliefs. The role of healthcare professionals is to ensure families receive clear information about the decisions that are available to them.
  
20. A model of psychological care for families and people with strong emotional attachments to the patient should be delivered using a stepped approach. This would involve professionals appropriately referring families for support from lay personnel, such as religious leaders, primary care mental health teams and GP counselling services, as well as third sector support. However, given the complexity of the emotional and psychological experience of families, such as the 'ambiguous loss' experience access to specialist psychological support is also needed.
  
21. In the event of a parent being diagnosed with a disorder of consciousness, children and young people will require specialist support. Children with brain injured relatives have been referred to as the 'neglected victims' of brain injury, therefore their specific support needs should also be considered within a

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<sup>5</sup> "Family" is used as shorthand in this document to refer to all those who are engaged in caring for the patient or interested in his or her welfare (as set out in the Mental Capacity Act 2005), whether or not they are related to the patient.

comprehensive model of psychological care. Developing a psychologically informed care pathway will require an increase in resources and staff, including additional clinical neuropsychology to oversee the governance of the pathway.

22. Each case should be provided with a key care planner or co-ordinator. A planner could be a key individual or case manager, with links to appropriate individuals, who would oversee the communication and information provided to relevant parties ensuring the right thing is done at the right time by the right person, as per the principles of anticipatory care. This role could be undertaken by healthcare professionals from a variety of backgrounds such as members of the multi-disciplinary or primary care team, as the family may wish to deal with a professional they have a long standing relationship with. Whoever undertakes the role; must have the appropriate level of information and skills, ensure a support plan is in place and earn the confidence/trust of those concerned.
23. To help avoid complications regarding decision making and the personal wishes of the patient involved, a campaign to promote conversations in advance between individuals and their friends/relatives is recommended. These conversations would encourage individuals to consider their wishes in the event of entering a state of prolonged unconsciousness and ensure that their wishes are clearly heard at a stage when they lose capacity. This makes the best interests assessment process more straightforward and less burdensome for healthcare professionals and families.
24. Information for friends and families of those diagnosed is required in a format appropriate for the family. This can include leaflets, websites or videos. The advice provided needs to reassure, whilst providing honest, clear guidance.
25. It is also important for staff to access an appropriate environment/spaces to care for families and hold difficult conversations. Facilities need to be suitable to provide professionals the ability to work together to support families in a multidisciplinary manner.

Professional Education / Upskilling / Support

26. The majority of healthcare professionals are unlikely to ever be presented with these cases. In the event a case presents, it is that there are important referral pathways and information are easily accessible for colleagues who do not have regular exposure to this specialised area of medicine. Colleagues also need to utilise the expertise of health professionals with specific training in this area. Any guidance must focus upon the best interests of the patients, rather than take a standardised, one size fits all approach.
27. There are also staff in private, NHS or social care settings that care for patients in these conditions, but may not be adequately aware of the conditions. Therefore, a training programme should be instigated for staff most likely to come into contact with these patients. This training should include how to recognise these conditions and improve diagnostic accuracy. It should also provide expert training to widen understanding and develop competence in relation to the treatment/care for these patients.
28. Professionals must consider methods of communicating between each other the needs of these patients. Communication training, peer review and more direct handovers could avoid ambiguity and result in improved support and care for the patient and their family.
29. Often health professionals can inadvertently provide families with information that provides false hope. Although well intentioned, this can be harmful. Health professionals need to be aware of the importance of wording when explaining clinical information. The information provided must be unbiased, honest, realistic and avoid providing families with false hope in terms of outcome.
30. The RCP guidance recognises there is often genuine uncertainty about the patient's condition/prognosis until evaluation is complete, it is important to keep open lines of communication and a free exchange of information as evaluation progresses and the picture clarifies.

31. Provision of psychological care, training, supervision and reflective practice for staff is recommended to support the wellbeing and sustainability of the health professionals working in this area and to promote effective family support at all levels.

#### Inreach and outreach programmes

32. Specialist services for the diagnosis and ongoing care of patients with a prolonged disorder of consciousness in Wales are currently available to treat in-patients only. An outreach programme would allow for staff to visit prospective patients in their locations, make assessments without disturbing the patient, free up capacity at specialist centres and help families often in their own homes.
33. Providing outreach services into critical care or other clinical specialties would aid earlier identification of patients and help ensure care is undertaken in best interests of the patient.

#### Pathways

34. Two separate pathways are required dependent on the circumstances of the patient. One is required for existing patients, considering their care to date, ensuring the families receive the support and information required to ensure decisions are made in the patients best interests..
35. Another pathway is required for new patients. This will focus on ensuring that diagnosis is as accurate as possible and providing early support to families.
36. Any pathway will need to be easy to understand and navigate, as well as clearly setting out referral processes for non specialist clinicians. They should refer to guidance already developed and align with other services including major trauma, stroke and critical care. Consideration also needs to be given to the role of end of life care, within these pathways.



## Conclusion

37. The task and finish group was established to consider services for adults who have a prolonged disorder of consciousness. It was also asked to make recommendations to support the process of planning and delivery of services, as well as provision for staff in dealing with such issues.
38. The group concluded that the identification and care for adults with PDOC requires development to improve diagnosis and treatment for patients in Wales as well as guidance for health professionals.
39. Whilst there is awareness of existing guidance relating to the treatment of patients, the general awareness in relation to services provided by specialist neuro-rehabilitation teams is extremely low amongst the wider staff within the NHS and consequently pathways are inconsistent.
40. The diverse range of locations and services providing care to patients with these conditions often results in them being difficult to identify. Patients may not receive a confirmed diagnosis and receive disjointed care, making best interest decisions following appropriate consultation or consideration of provision for all treatments difficult.
41. Development in these areas is required across health and social care to address the issues identified. Health boards need to work collaboratively to identify these patients and establish all Wales pathways to optimise care across sectors for these patients and their families, whilst ensuring best interests are considered.
42. This report represents the first step to improve services for people who may be or are in a prolonged disorder of consciousness. Further detailed work is required to identify the number of prevalent cases, develop a business case to appropriately resource the services required and ensure appropriate pathways.

## **Recommendations**

### Identifying patients / Existing cases

Work is required across Wales to establish an accurate understanding of the number of patients and the care/treatment they are receiving. We recommend that:

1. Assess the prevalence of existing cases, using a range of methods.
2. Consider the development of a register or audit of patients in these conditions to ensure the care and treatment of both current and future patients can be regularly reviewed.

### Family Support

Families need extensive support to ensure they are fully informed and help enable them to make difficult decisions about the future treatment. We recommend the support they are provided should include:

3. Psychologically informed care pathway to be implemented with all families, with an approach tailored to each individual circumstance.
4. Each family of an individual who is in a prolonged disorder of consciousness should be provided with a key care planner.
5. Easy read and accessible guidance should be developed for families and utilised to help families understand the diagnosis, treatment support and potential outcome.
6. Conversations between health professionals and families should be undertaken in an appropriate space.

### Professional Education / Upskilling / Support

It is recognised that for many healthcare professionals providing treatment and care for a patient in a prolonged disorder of consciousness will be an extremely rare event. It is also recognised these cases can have a significant emotional impact on the staff. We recommend:

7. Improved availability and guidance for non-specialist staff.

8. Creating a simplified document providing a pathway for patients.
9. Providing specific training for all healthcare professionals most likely to come into contact with patients in these disorders, including the avoidance of providing false hope to families.
10. Ensuring staff have access to short and long term support, as well as time, to process their reactions to handling such cases
11. Ensure all health and social care staff receive appropriate training in the principles of the Mental Capacity Act and holding best interest conversations.

#### Inreach and outreach programmes

The Group acknowledged that the services currently provided for these patients are not adequately commissioned to provide the resources required to adequately diagnose and provide ongoing management/support. We recommend the current service is expanded including:

12. Developing an out-reach programme for adults with potential prolonged disorder of consciousness both within a clinical setting or within the community.

#### Pathways

The Group recognises current pathways for these patients are not clearly defined in Wales; we recommend a set of pathways is developed:

13. For assessment of existing patients.
14. Specialist and general pathways for new patients which must be easy to navigate, clearly set out referral processes and be able to be utilised anywhere in Wales.

#### General

15. As part of any campaign to actively promote advanced discussion conversations between individuals and their relatives, consideration should

be given to promoting conversation about their wishes in the event of entering a prolonged disorder of consciousness – including, specifically, whether they would want clinically-assisted nutrition and hydration to be continued or not. This should include information about how to make their wishes known, either informally or formally through the use of an advance decision to refuse treatment (ADRT) or lasting power of attorney (LPA).

## **Appendix 1 - Terms of reference**

The task and finish group will consider services for those people who have a prolonged disorder of consciousness, including whether the diagnosis, care and treatment is in line with legislative requirements such as the Mental Capacity Act 2005, Social Services and Well-being Act 2014 and national guidance such as Welsh Government Continuing Health Care Guidance and Royal College of Physicians Guidance on Prolonged Disorders of Consciousness – National Clinical Guidelines.

To make recommendations to support the process of planning and delivery of services for the diagnosis, treatment and support for people and their families/carers including any suggested training needs or provision for staff in dealing with such issues.

To submit a report by end of June 2018 to the Welsh Government with recommendations on improvements to achieve optimal clinical outcomes and patient experience, including appropriate referral, treatment and decision making pathways.

In fulfilling its terms of reference, the Task and Finish Group will take account of:

- Current relevant policy and guidance including any new guidance published the lifetime of the group
- Current work being undertaken by health boards
- Court of protection judgements
- Recommendations arising from the independent review led by Baroness Professor Finlay of Llandaff

### **Membership**

- Chair – Prof Chris Jones, Deputy Chief Medical Officer#
- Representatives from Specialist service in Rookwood
- AMD for primary care
- Nursing representative
- AHP representative
- Representative from Wales Critical Care and Trauma Network
- Representative from Welsh Intensive Care Society
- Representative from Association of British Neurologists
- National Clinical Lead for Respiratory or Representative from Respiratory Implementation Group
- Representative from the End of Life Care Implementation Board
- Representative from Social Services
- Representative from Welsh Health Specialised Services Committee
- Representative from NHS Wales Shared Services Partnership – Legal & Risk Services
  
- Policy Leads Welsh Government

Others may be co-opted on by members of the Task and Finish Group as required.