

Where can I find out more?

For further information about PDOC please see:



<https://www.healthtalk.org/family-experiences-vegetative-and-minimally-conscious-states/overview>



<https://cdoc.org.uk/publications/resources-for-families-and-practitioners/>



<https://www.rcplondon.ac.uk/guidelines-policy/prolonged-disorders-consciousness-following-sudden-onset-brain-injury-national-clinical-guidelines>

Annex 4b

Updated August 2022



Prolonged Disorder of Consciousness (PDOC)

A guide for families, friends, carers and those working with individuals in PDOC

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Canolfan Llandochau am am Adsefydlu Arbennigol yr Asgwrn Cefn a Niwro /
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How long can a PDOC assessment take?

The period of assessment will vary depending on the individual's needs but generally takes 3 weeks for initial assessment and could take up to 12 weeks for the whole process. The tests are repeated over time to consider that a person who is completely unaware may make random sounds or movements that could be mistaken for a deliberate response and also that if someone is minimally conscious they may sometimes respond, and sometimes not so repeat testing ensure no response are missed.

How can family, friends or carers help?

Families and friends of individuals in PDOC have a valuable role throughout the assessment process, and in contributing to the decision-making processes. Individuals can respond differently with family and carers so your input is extremely important. You will be asked to fill out bed side observation forms or diary to record responses that you observe. Staff working with the individual may also use these to record any responses they have observed. Your unique relationship with the individual means that you can provide important insights into their interests and preferences.

What does PDOC mean?

PDOC stands for Prolonged Disorder of Consciousness which encompasses both vegetative state (VS) and minimally conscious state (MCS). A "Disorder of Consciousness" refers to an individual who shows no (or minimal) awareness of themselves and their environment following a severe brain injury. The word 'Prolonged' in PDOC is important because it highlights that this disorder has gone on for some time which usually means the person has very severe brain injuries.

Some people with PDOC will progress through different stages of consciousness as they emerge into a state of full consciousness (although they are still likely to have profound and permanent disabilities). Some, however, will remain in VS or MCS for the rest of their lives.

Emergence from MCS is characterised by reliable and consistent demonstration of either meaningful interactive communication, or being able to use objects in a purposeful way (or both of these things).

Why assess?

Formal PDOC assessment is often recommended but it is **not** essential. As the individual with PDOC cannot give consent to these assessments for themselves, it is important for the Senior Clinician to make decisions on their behalf that reflects their prior wishes, values, feelings and beliefs. This is true of all decisions made about them, including those around life-sustaining treatment. This is called a 'Best Interests' decision.

You should be involved in the decisions about the individual's care before, during, or after PDOC assessment is completed, or even without a PDOC assessment at all. It is important to involve you because you knew the individual before their injury and can let the clinical team know what decision you think the person themselves might have made in this situation (Please see separate information booklet on the role of family and friends in decisions around life sustaining treatment in PDOC– Annex 4b RCP PDOC Guidelines).

What is the aim of a PDOC assessment?

The aim of assessment is to confirm a PDOC diagnosis and to establish where the individual is on the spectrum of Disorder of Consciousness. This can help inform whether the person's level of consciousness may change in the future or not, and guide future care planning and decision making.

What does a PDOC assessment entail?

There are 3 different assessments that could be used in assessing PDOC which are:

- WHIM (Wessex Head Injury Matrix)
- CRS-R (Coma Recovery Scale – Revised)
- SMART (Sensory Modality Assessment and Rehabilitation Technique)

These assessments have been developed specifically for identifying whether there is any awareness in individuals who have PDOC following severe brain injury.

Who carries out PDOC assessments?

Only staff who have knowledge and experience of working with PDOC should carry out these assessments. This could be an Occupational Therapist, Speech and Language Therapist or other Health Professional, and they will have had special training to make sure they know how to carry out the assessments and interpret the results.

What happens during the PDOC assessment process?

The PDOC assessor will work with the family and the whole team to ensure that the individual is given the best opportunity to respond during the assessment period. For example, to ensure that they are positioned correctly to help them see and move. The assessor then uses a range of techniques to assess the person's responses to vision, hearing and touch. Movement, communication and wakefulness are also considered. The assessor will also work with you to hear about any responses that you may have observed.