



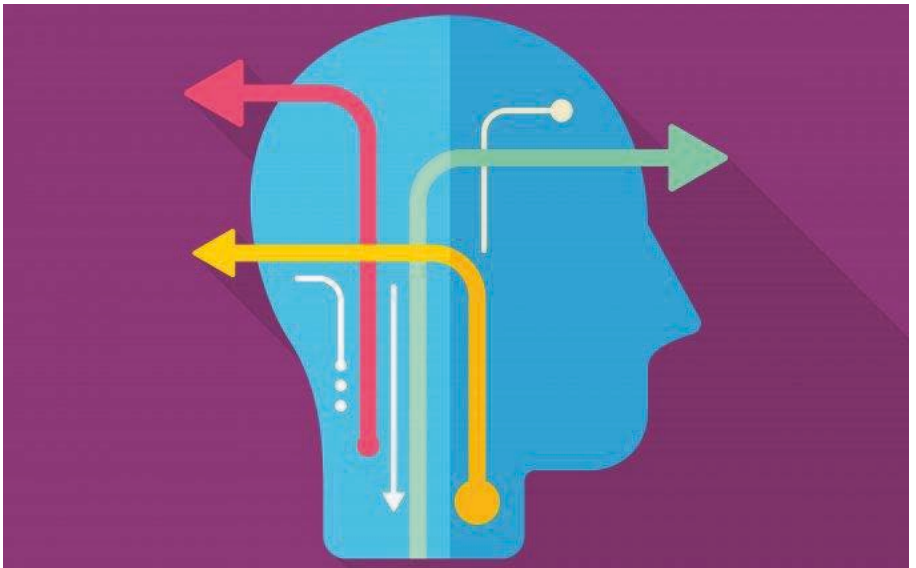
Holly Unit



National Rehabilitation
University Hospital

An tOspidéal Náisiúnta Athshlánúcháin

Prolonged Disorders of Consciousness (PDoC)



**A Guide for
Families, Friends and Carers**

This booklet aims to provide information and support to families of people admitted to Holly Unit in the National Rehabilitation Hospital (NRH).

Holly Unit is part of the Brain Injury Programme in the NRH. It has five inpatient beds reserved for people in Prolonged Disorders of Consciousness (PDoC). In this booklet you will find information on what to expect during a patient's admission to Holly Unit. Please ask any member of the team if you would like to discuss any of this information further.

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What is Consciousness?

Consciousness

Consciousness is controlled by different parts of the brain. Consciousness allows a person to be alert, aware of themselves, aware of others and aware of the environment around them. It is made up of two essential components, wakefulness and awareness:

Wakefulness

Wakefulness is also referred to as arousal, that is a person's ability to open and close their eyes and demonstrate periods of being asleep and periods of being awake.

Awareness

Awareness is a person's understanding of themselves and what is happening around them. A person's level of awareness can be observed by the behaviours they show. A behaviour is an action that may include: following a person moving across a room with their eyes, jerking in response to a loud noise, using an object appropriately, or following an instruction.

A person needs to have both consistent wakefulness and awareness to be conscious. Many people are unconscious after a brain injury, sometimes for a matter of seconds and sometimes for longer. In some cases, the person may not be fully conscious for weeks or even longer after their injury. There are different levels of how aware and awake someone can be.



Figure 1 – What is Consciousness?

What are Disorders of Consciousness?

Disorders of Consciousness is the name given to the different conditions people can have where consciousness has been affected by damage to their brain. If it lasts for more than four weeks it is sometimes called 'Prolonged Disorders of Consciousness'. For the remainder of the document, Prolonged Disorder of Consciousness will be referred to as PDoC.

There are three different types (or 'levels') of PDoC. People can move through these different levels. Some people may emerge from a PDoC. This is called emergence.

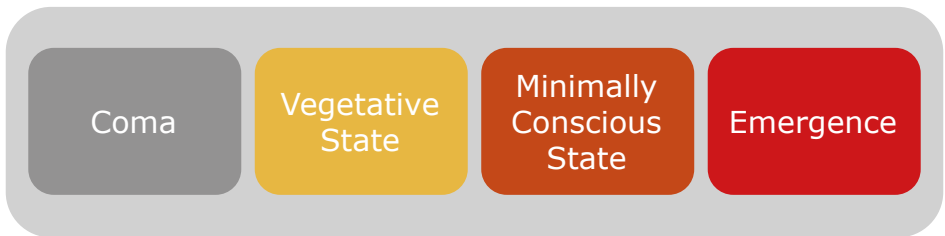


Figure 2 – Levels of Consciousness

Level 1: Coma

A person may spend some time in a coma after a significant brain injury. A coma means a person has their eyes closed and they can't be woken (they do not show signs of wakefulness). This means they are not aware of their surroundings or themselves. Some people will move from this level to a 'vegetative state'.

Level 2: Vegetative State

A person in a vegetative state will have periods where they are awake and where they are asleep (although not necessarily in their normal pattern). Although they appear to be awake, they do not show awareness of themselves or what is happening around them.

The things that people do in a vegetative state are reflexive in nature, for example, coughing, swallowing and blinking. This can be a permanent state for some people. Sometimes a person will move to a different level of recovery, for example, the minimally conscious state.

Level 3: Minimally Conscious State

A person in a minimally conscious state will have periods where they are awake and where they are asleep (although not necessarily in their normal pattern). Unlike the vegetative state, the person in a minimally conscious state will show signs of purposeful behaviour, that is, things they mean to do. They might follow a person or an object with their eyes, or look at an object on request (or 'to command'). Behaviours are not just reflexive, they are intentional and reproducible. These behaviours are often subtle and don't happen all of the time (they are 'inconsistent').

Like the vegetative state, this state may be permanent or may be a stage that leads to further recovery. The vegetative state and the minimally conscious state are also called a 'low awareness state'.

Emergence

Emergence from a minimally conscious state is evident when a person meets specific criteria in their ability to demonstrate reliable and consistent responses. Examples include being able to use a hairbrush reliably and consistently or being able to give a correct 'Yes' or 'No' response to specific questions. Persons may emerge from PDoC but may continue to have significant changes in their thinking skills as well as physical limitations.

Locked-in Syndrome

Locked-in-Syndrome is **not** a PDoC. A person with locked-in-syndrome demonstrates wakefulness. They are **aware** of themselves, aware of others and aware of their environment. However, a person's ability to demonstrate such skills can be limited due to paralysis and so they may rely on alternative means to communicate and engage with people and their environment.

What causes a Disorder of Consciousness?

A PDoC happens when areas of the brain that are responsible for consciousness are damaged. This damage to the brain can occur in a number of different ways:

- **A traumatic brain injury:** this involves a sudden force which causes severe injury to the brain, such as a fall, road traffic accident, assault, or sports related injury.
- **An acquired brain injury:** this includes traumatic brain injury as well as other causes such as stroke, heart attack, drug overdose, suffocation, drowning, an infection such as meningitis and other conditions, for example, brain tumours.

Recovery of Consciousness and Treatment of People in PDoC

Recovery - what do we know?

The most crucial recovery of consciousness happens in the first weeks and months after the injury. We do know that the longer someone is in PDoC, the less likely they are to recover from PDoC. However, every person and every brain injury is different. The NRH team will be able to talk about this in more detail.

Treatment of PDoC

Interventions for people in PDoC are individualised and will depend on each person's specific presentation and needs. The Holly Team will carry out assessments throughout the patient's admission to determine their treatment needs. Interventions for people in PDoC often focus on optimising quality of life through a range of treatments, which you can read about later in this booklet.

Caring for a person in PDoC

Basic Needs

A person in PDoC is dependent on others to meet their care needs. Examples of such care needs may include the following:

- Regular and good standards of oral and dental care
- Providing nutrition through the feeding tube
- Bladder and bowel care
- Keeping skin clean and healthy to prevent the person from developing pressure injuries
- If applicable, tracheostomy care and weaning
- Reviewing and monitoring medications
- Provision of specialist equipment such as hoists, shower trolleys or shower-chairs for the duration of their admission to the NRH to facilitate safety and comfort during washing and dressing

Medication

Some of the common medications prescribed for a person in Disorder of Consciousness may include:

- Medication to reduce the risk of epilepsy or seizures
- Medication to prevent or improve any stiffness in the muscles
- Medication to prevent poor alertness or drowsiness (avoiding sedating effects)
- Medication to alleviate and reduce any signs of pain
- Medications to treat infections

Nutrition and Hydration

People in PDoC often need to be fed by a feeding tube that goes into the stomach. This is usually known as a PEG tube (Percutaneous Endoscopic Gastrostomy). Specific quantities of feed and water are fed through the PEG to ensure the person meets their nutritional and hydrational needs.

There can be times when a person may have an ability to eat and drink orally also. If this is the case for your family member, the team will discuss this with you in further detail.

Positioning

The person in PDoC will require a 24-hour posture management plan. They should be positioned safely and comfortably to minimise the development of secondary complications, such as pressure injuries and contractures, and to optimise daily care. The appropriate positioning plan will also optimise the person's levels of alertness and potential to interact with the environment and with other people.

The Holly Team will work together to develop an individualised posture management plan for your family member. Your physiotherapist can discuss this with you in further detail.

Assessment of Awareness

The NRH team may assess the patient's awareness. The purpose of assessment of awareness is to establish if a person in PDoC is:

- Wakeful
- Aware of themselves, others and the environment

Assessing awareness can provide us with important information. For example, as well as establishing the person's level of awareness, it can help us to establish their ability to understand, their ability to communicate and their ability to move.

Assessment Process

To assess a person's awareness, their team in the NRH will look at how they are at rest and how they respond to different stimuli, for example, how they respond to tasting, touching, hearing, smelling and seeing different items. The team will also consider medical information such as brain imaging reports and information from family in the assessment process.

Assessment is carried out by a team of people; Doctors, Nurses, Physiotherapists, Speech and Language Therapists, Occupational Therapists, Psychologists, Music Therapists and Medical Social Workers. Family are also an important part of the assessment process.

Family can help to establish what might be most meaningful to the patient. This information can be incorporated into team assessments. For example, family can help the team to understand the person's likes and dislikes which may influence how they respond to different stimuli.

Assessment of Awareness Process

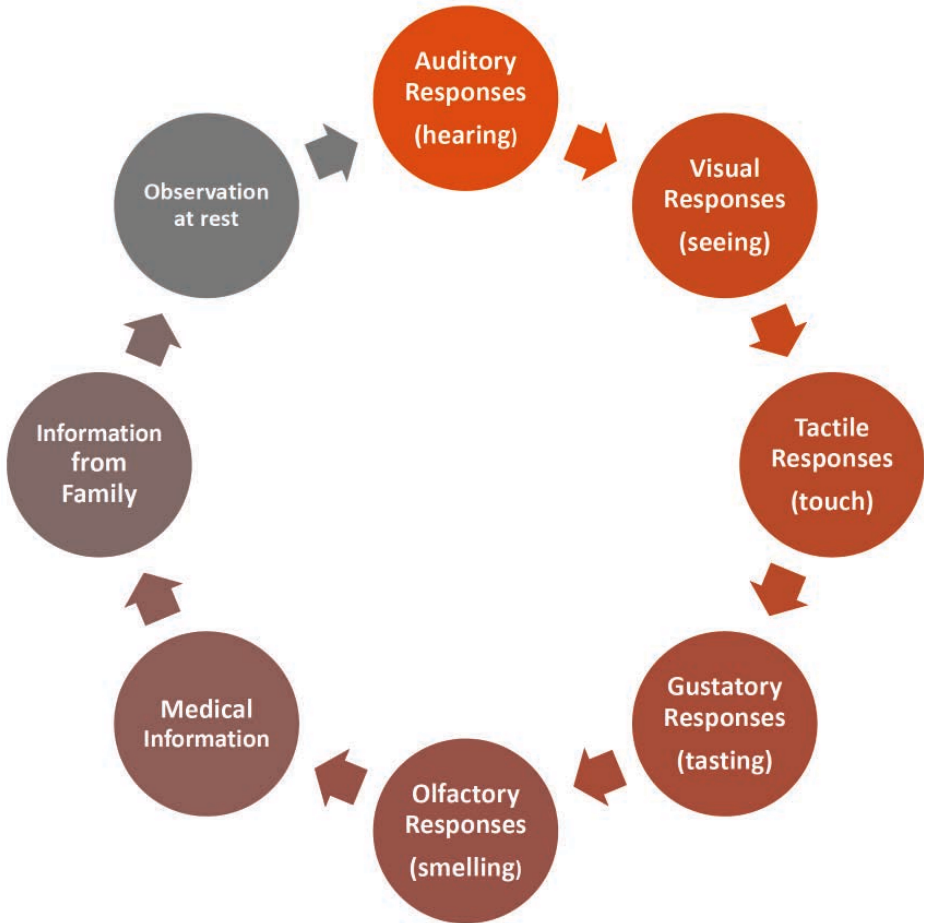


Figure 3 – Assessment of Awareness Process

What can Family do?

Family members can play a very important role in supporting the therapy team to help the person in PDoC.

Sensory Regulation

Each person processes information through seeing, hearing, touching, tasting and smelling. However, when a PDoC occurs, the person will experience difficulty regulating this information and can become overloaded. A person may demonstrate sensory overload by closing their eyes, grinding their teeth, moaning or moving continuously.

By regulating sensory stimulation for a person in PDoC, you are helping them process the sensory information that they receive. This in turn will help with alertness.

How do you regulate sensory information?

- Planning times for family visits and telling staff when you intend to visit. This can help staff plan therapy sessions and interventions, to make sure your family member is not over stimulated and fatigued.
- Allow your family member to rest for a time during your visits. You can create a restful space by dimming lights, minimising noise, closing the door or curtains where appropriate, making sure they are comfortable, and telling them how long their rest will be for.
- When the patient is resting, try to avoid talking or touching them during their rest periods as this may reduce the quality of their rest. It's fine to sit with them while they rest.
- If the patient is resting during your visit, spend time observing their movements and behaviours. They might do things differently at rest. This information can then be discussed with the therapy staff. You may wish to write this down and share what you have seen or heard with the team.

- If the patient is well rested, a good way of spending time together is with some basic sensory stimulation. Some examples of which are:

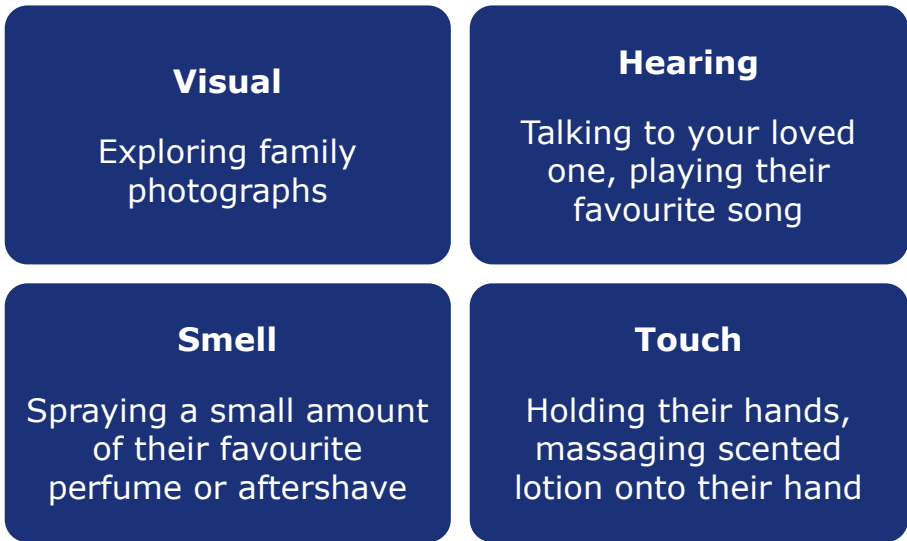


Figure 4 – Examples of Sensory Stimulation

When spending time with your family member, if you can, speak slowly to them while keeping your communication natural. Always tell the person what you are going to do before you do it, for example “I’m going to spray some perfume on your right hand now”. Try to have one person speaking to your family member at a time. Give them time to respond and allow some time between activities.

Family Meetings and Decision Making

The involvement and support of families in patient care is greatly valued in the NRH. Family meetings will be organised at different times during your Family Meetings and Decision Making admission.

Early on in their NRH admission, the Holly Team aim to meet family members of people in PDoC so that they can better get to know the person and what their wishes might be, if they could communicate them. This is an opportunity for the team and family to explore relevant decisions together to best support the person in PDoC.

Decisions that may be discussed at this initial meeting include decisions related to the person's resuscitation status, care needs and discharge locations. However, the process of establishing the person's wishes and ensuring we are acting in line with them is ongoing throughout their admission.

Further meetings will be held throughout the person's admission, as and when decisions need to be made. The NRH team will also be able to guide family around organising formal decision-making support arrangements where needed.

Family meetings will also be held during the admission to discuss goals and expectations for their admission, to update you on their progress and to give family an opportunity to ask any questions they may have.

Support for Families and Carers

Brain injury not only impacts the person, but also their family and friends. Family members of a person in PDoC can experience a range of emotions. Many people describe experiencing a sense of grief or loss when someone close to them has a severe brain injury. The type of loss experienced in these situations is sometimes referred to as 'ambiguous loss'. Ambiguous loss is a loss which is unresolved and in which there is uncertainty (in the case of PDoC, uncertainty as to the person's recovery or their future).

Some family members describe feeling as though they are 'in limbo' or that their family member is 'there but not there'. Sometimes people experience mixed emotions. People can be happy that the person has survived whilst also grieving for the loss of the relationship they had with their family member before their brain injury.

When a sudden life-changing event like a severe brain injury occurs in a family, everyday life is often put on hold. When someone is in PDoC, progress can be very slow. For family members and carers this can be very challenging. It is important therefore that family members look after their own mental and physical health.

Some families find having a visiting schedule helpful, while others may find that they turn to previously enjoyed leisure activities for their own wellbeing. Looking after their own wellbeing will often allow family members to spend better quality time with their loved one.

Psychology and social work supports are available to family members during their family member's admission to the NRH. See a list of support services for families on the following page which may also be useful and which a team member in the NRH can talk through with you.

Support Services and Resources

Headway Brain Injury Services and Acquired Brain Injury Ireland (ABII) offer a range of supports, such as psychology support, to family members of people with brain injury. These services are both free of charge. The NRH Team can support you with a referral to ABII or Headway, or you can also contact these services yourself or visit their websites for further information.

Headway Ireland, Brain Injury Services & Support

Website: www.headway.ie

Phone: 1800 400 478

Acquired Brain Injury Ireland (ABII)

Website: www.abiireland.ie

Phone: 01 280 4164

Healthtalk Website

The 'Healthtalk' website has information on PDoC as well as videos of family members talking about their experiences. You can access this information by following the link below:

www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/overview



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