Headway
the brain injury association

Prolonged disorders of consciousness after brain injury

This publication is for the familiesand loved ones of a patient in a vegetative state or a minimally conscious state after brain injury (collectively known as prolonged disorders of consciousness). It describes what happens during these states, how you can look after yourself through this difficult time and what may happen next.

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Introduction

This publication is for the families and loved ones of a patient in a vegetative state or a minimally conscious state after brain injury. These states are collectively termed Prolonged Disorders of Consciousness (PDOCs).

We understand that this is likely a very difficult time. You will probably have many questions and concerns that the medical team are unfortunately unable to address right now. You might also be dealing with a significant change in your circumstances and many difficult emotions.

With so much on your mind, it might be difficult to take information in, especially where this might seem confusing or very technical. We encourage you to take your time with working through this document, focusing on the sections most relevant to your personal circumstances. The contents section should be able to help with this. You do not have to read this publication all in one go, and you can return to sections as often as is helpful.

A glossary of key terms is also included at the end of this publication.

The information in this publication does not replace clinical guidance from medical professionals.

What are prolonged disorders of consciousness?

Prolonged disorders of consciousness (PDOCs) are states of reduced consciousness that can affect people following serious brain injury. They are distinct from a coma, which is a complete loss of consciousness lasting over 6 hours. However, many people who are initially in a coma progress to a PDOC state. More information on comas is available in our publication Coma after brain injury.

The two types of PDOCs are vegetative state and minimally conscious state.

- A *vegetative state (VS)* is a state in which a person has periods of time where they are awake, and periods of time when they are asleep. A person in VS has no awareness of themselves or their surroundings.
- A *minimally conscious state (MCS)* is a state in which a person also has periods of time when they are awake and periods of time when they are asleep. However, a person

in MCS is sometimes aware of themselves and their surroundings.

The following sections explain these states in further detail.

Vegetative state

A vegetative state (VS) is a state in which a person:

- is awake but unaware - this means that they will look like they are awake as their eyes will sometimes be open, but they will be unaware of their surroundings or themselves;

- is able to reflexively react to stimuli (such as light or sound), for instance turning their eyes towards a loud sound;

- may have some spontaneous behaviour, such as moving their arms or legs, making grunting or groaning sounds, or grinding their teeth.

Unfortunately, none of these behaviours are done with conscious intent. Therefore, while it is often tempting for family to think that someone displaying these behaviours is reacting to something they have said or done, in VS this is sadly not the case.

Even if a person in VS smiles, sheds tears, changes their facial expression or moves their eyes around after a family member has said or done something, this is probably a coincidence at this stage. However, if this happens frequently, or the behaviour appears to be intentionally oriented to the surroundings (such as attempting to reach out for an object after someone has named the object), it might be helpful to mention this to the clinical and nursing team. You can also discuss the option of recording your interactions with your loved one, and reviewing the recordings with the clinical team.

Some people find the term ‘vegetative’ upsetting and offensive, but the term ‘vegetative’ is nothing to do with ‘vegetable’, and instead originates from the clinical features of this state.

Classifications

A person who remains in a VS for over 4 weeks can be classified as having ‘continuing VS’. If the person remains in a VS for over 1 year following traumatic brain injury, or over 3 months following an anoxic or other metabolic brain injury, they can be classified as having ‘chronic VS’.

The features and classifications of VS can be complex and difficult to distinguish. They are only included in this publication for awareness and to offer familiarity with some of the terms you may hear being used by the clinical team involved in your loved one’s care.

You should not attempt to diagnose or classify your loved one’s condition yourself, as only highly specialised clinicians are able to do this. However, if there is a term being used that you do not understand or feel you need more information on, don’t hesitate to ask nursing or clinical staff to explain this to you.

Minimally conscious state

A minimally conscious state (MCS) is a state in which a person:

- has severely altered consciousness;
- can interact with their surroundings to some degree;
- has periods of behaving in a way that shows minimal but clear awareness of their environment or themselves.

The behaviours showing awareness and interaction are not, however, done in a consistent way.

Classifications

There may be periods where the person in an MCS is able to interact with their environment and others, which can include communicating with family and problem-solving. This is classified as ‘MCS-plus’.

People who can show skills such as purposefully tracking movements or sounds, but are not able to interact further with their environment, are classified as ‘MCS-minus’.

These classifications are used to distinguish between the level of MCS someone may be in.

A person who remains in an MCS (either ‘plus’ or ‘minus’) for over 4 weeks can be classified as having ‘continuing MCS’.

If a person remains in MCS-minus for more than 1 year following traumatic brain injury, or more than 3 months following anoxic or other metabolic brain injury, they can be classified as having ‘chronic MCS-minus’. If a person remains in MCS-plus for more than 18 months following traumatic brain injury, or more than 9 months following anoxic or other metabolic brain injury, they can be classified as having ‘chronic MCS-plus’.

The features and classifications of MCS can be complex and difficult to distinguish. They are only included in this publication for awareness and to offer familiarity with some of the terms you may hear being used by the clinical team involved in your loved one’s care.

You should not attempt to diagnose or classify your loved one’s condition yourself, as only highly specialised clinicians are able to do this. However, if there is a term being used that you do not understand or feel you need more information on, don’t hesitate to ask nursing or clinical staff to explain this to you.

Treating prolonged disorders of consciousness

Your loved one will initially be treated in a hospital intensive care unit.
They might need help from a machine to breathe, and artificial nutrition and hydration to be given through tubes. They might also have a catheter inserted to drain their bladder. There might therefore be lots of machines and monitors attached to them. These can make a lot of noise and frequently sound alarms, but this is usually nothing to be concerned about and is quite normal. Nurses will always be close by if anything is needed.

Your loved one will also be regularly re-positioned to prevent pressure ulcers from developing, and their joints will be gently exercised to prevent tightening. Their mouth and skin will also be cleaned.

Clinicians will monitor your loved one's condition and check for any changes to their level of consciousness using clinical tools and observations of behaviours. They will be assessed regularly to check for any changes.

Any decisions regarding your loved one's treatment will be made in their best interests. This means that while family and loved one's input may be considered, they do not have the legal authority to make decisions about treatment on their loved one's behalf, unless there is a pre-arranged, valid and registered Lasting Power of Attorney in place. In all cases, decisions regarding treatment and care should be situation-specific and made in the person's best interests.

Information about what your loved one themselves would prefer may already be available, for instance if they have already made an Advance Decision to Refuse Treatment, sometimes called a Living Will, before their injury.

Being involved in your loved one's care

It is natural for people to want to be involved in their loved one's care, as this can allow them to feel more connected and helpful.

You could ask nursing staff if there are ways for you to help with basic nursing tasks, such as wiping your loved one's face or brushing their hair. You should also be involved in discussions about their treatment, as families can often offer helpful information regarding the patient's wishes and preferences.

Some people feel that presenting their loved one with familiar stimuli might help them to emerge from a prolonged disorder of consciousness (PDOC) - for example, playing music that they enjoy, reading to them from their favourite books, talking to them about daily life events, showing them personal photographs or placing familiar objects in their hands.

Unfortunately, there is limited evidence for the effectiveness of these activities, but you can still ask nursing staff about this if you think it will be a helpful way for you to get involved.

These activities might be helpful if your loved one is in a state where they are able to respond to or enjoy the stimuli you present them with. However, remember not to introduce too many of these activities to your loved one, and not to do these too often, as they will need periods of rest and may become overwhelmed if overstimulated. Occupational therapists will already be making sure that the environment is appropriately set up for your loved one's needs. You should therefore only introduce these activities under clinical guidance.

Looking after yourself

Your top priority at this stage is likely to be the welfare of your loved one, and it is natural to want to spend most of your time at their bedside. You might be especially keen to be beside your loved one if they begin to regain some level of consciousness. However, it is important to focus on making an effort to look after yourself through this difficult time too.

Here are some things that you can do to look after yourself during this time:

- **Take regular breaks** from your loved one's bedside. You do not have to be beside them all of the time, and will be able to cope much better if you take frequent breaks. If you want to stay on site to be close by, most hospitals have quiet rooms that you can use. It might be possible to arrange for a rota of family members visiting, but try not to include too many people visiting at once, as this may become overstimulating for your loved one.

- **Accept as much help as you can get** from family and friends, for example accepting offers for cooking meals, cleaning the house or picking children up from school. Remember that accepting help is a sign of strength, not weakness, and your loved ones will be keen to help however they can.

- **Keep your employer informed of the situation**. Your employer may be able to grant you time off or change your workload so that it is more manageable for you.

- Remember to **eat a healthy, balanced diet** during this time, and if possible, try to take some time to do activities that you enjoy or can help you to relax. Try not to feel

guilty about this, as it is important for you to look after your wellbeing through this difficult time.

- If you jointly pay bills with your loved one and are struggling to meet payments, **talk things through with your bank or service provider**. It may be possible to reschedule any payments and budget for your new circumstances.

- **Talk to others about how you are feeling**. This can be with family, close friends, or other families in the unit if they seem comfortable with talking. Do consider, however, that everyone's situation is different, and some families may not want to talk about their circumstances. You can also contact our nurse-led helpline for information or emotional support, or use our online communities to connect with others in similar situations - more information on these services is in the section *How can Headway help?*

Looking after children

Families with children may have unique challenges to face in terms of considering how much information to share, whether to bring them along for hospital visits, how to approach difficult conversations and what to do to best support the child through this time.

How much you choose to share and involve children will depend on the child's age and their level of understanding. It usually helps to tell children of any age, even very young ages, something of what's going on as children are very sensitive to changes and will worry if they notice that something is different but do not know why.

You will know your child best, so will be best placed to assess what and how to tell them about the circumstances. However, some general considerations are given in this section.

- Give the child time to talk about how they are feeling. They can do this through discussions, writing, drawing or play. You should also allow the child time to talk about other things such as homework, activities or their friends.

- Try to avoid telling children that ‘daddy or mummy is asleep’, as this may make them fearful about falling asleep or waking up again. Similarly, try to avoid making promises about their parent coming home and when this will be, as children need to know that they can rely on what they are being told. Unfortunately, no one can say this for certain, even if your loved one is gradually regaining consciousness.

- Keep the child’s school informed of the situation so that their teachers can support them appropriately.

- Don’t feel that you have to constantly put on a brave face around the child - it is okay to show your feelings, as this may encourage them to express themselves as well. Sometimes, children wait to see an adult’s response to a situation to get ‘permission’ for expressing themselves as well.

- Reassure the child that it is okay for them to be sad and anxious, rather than telling them not to worry. These are natural emotions and children should not be made to feel that they have to hide how they are feeling. At the same time, reassure them that it is okay for them to laugh and have fun - they are not being disloyal or insensitive by

doing so.

- If you are thinking about planning a visit with the child, ask them to tell you how they honestly feel about this and do not force them to go if they do not want to. Prepare them by explaining some of what they might see, such as any physical injuries that make your loved one look different - and then check with them again if they still want to visit. You could also agree beforehand on a code word that they say if at any point they want to leave during the visit.

Further information on this is available in our publication *Supporting children when a parent has had a brain injury*.

Emerging from prolonged disorders of consciousness

Clinicians will be regularly monitoring your loved one for any changes to their condition. However, it is unfortunately impossible to tell if and when someone will emerge from a prolonged disorder of consciousness (PDOC). This unpredictability can be one of the hardest things for family and loved ones to accept.

Patients that are initially in a coma may progress from the coma to VS or MCS.

Over time, people in a VS might begin to show signs of limited awareness, enabling them to be reclassified by clinicians as being in an MCS.

People in an MCS may further progress to regaining consciousness. This is demonstrated by their being able to communicate (either through writing, using ‘yes’/’no’ signals or using communication devices) and appropriately use at least two different objects.

In cases where people emerge from PDOC to eventually regain full consciousness, there may still be significant disabilities requiring input from rehabilitation teams. However, with the right input, even after emerging from a PDOC, people can and often do go onto recovering from brain injury and living fulfilling lives.

Permanent prolonged disorders of consciousness

It is important to state that in some cases, a person may be classified as being in a 'permanent' prolonged disorder of consciousness (PDOC) state. This classification is given when the person has remained in a chronic state of VS or MCS with no change for 6 months. In this case, they are likely to have severe, permanently disability if and when they emerge.

This classification may also be given if the possibility of the person regaining consciousness in future is highly improbable, for instance if they have sustained a very serious injury.

In these cases, it might be necessary to think about long-term care for the person and next steps.

This can be a very difficult thing for families to think about, but it is important to be aware of all possible outcomes. The team involved in your loved one's care should sensitively and thoughtfully discuss next steps with you. Any decisions relating to your loved one's care should always be made in their best interests. Further information on these matters is available in the following sections.

Long-term care

If a person remains in a state of PDOC for a long time, it may be necessary to consider transferring them to a suitable facility

to continue caring for their needs. For instance, a person may be transferred to a nursing or care home where they are able to continue receiving specialist care. A person should never be transferred to a facility that is not suitably equipped to support their needs.

Some families may consider bringing their loved one home. They may feel that their loved one will be more comfortable in a familiar environment.

Bringing a loved one home is a big responsibility and should be very carefully thought through in terms of the practical arrangements required and the emotional impact of taking on a full-time and demanding caring role. Specialist equipment and intensive treatment will be required, and the family will likely need to revolve their daily life around caring for their loved one.

The decision of where a person in a state of PDOC should be transferred should always be made in their best interests. Input from family can be helpful, but should always be given based on what the person themselves would most likely want rather than what the family want.

Withdrawal of treatment

Unfortunately, in some cases of severe injury, continuing to treat someone in a state of PDOC may no longer be of any benefit to them, or may only be prolonging a death that would naturally have happened at the time of the injury. In these cases, withdrawal of the person's care may be considered.

This is a very difficult decision to make for all involved, and will be particularly distressing for families.

Any decisions regarding withdrawal of treatment will always be made in your loved one's best interests, for instance if their

brain injury is so severe that they are unlikely to ever regain any quality of life.

Any decisions about withdrawal of treatment should always be made under medical, ethical and legal frameworks, and should involve the family and specialists.

In cases where there is a disagreement between family and the clinical team, the case can be referred to the Court of Protection and examined under legal proceedings. Loved ones are allowed to make these applications to the Court of Protection if they have concerns about withdrawal of treatment decisions.

If it is agreed that the process for withdrawal of treatment will begin, nurses should explain the next steps to you very carefully and sensitively. You will be given the chance to spend time with your loved one, and should have the opportunity to ask any questions or raise any concerns that you may have.

The change that takes place over your loved one will be gradual, over a period of days and weeks. There is no standard way that treatment is withdrawn, as this will depend upon the treatment that your loved one has been receiving.

You should be offered appropriate emotional support and information throughout this process. Remember, there is no right or wrong way to feel during this time; all emotions are understandable.

The time after the loss of a loved one is often very difficult for people. There may be many mixed emotions, and you may not even know how to feel. In addition to dealing with the emotional consequences of the loss of a loved one, people may feel traumatised or distressed by their recent experiences.

Take your time with processing your feelings, and consider seeking support from bereavement services or counselling. If you are struggling, consider talking to your GP about accessing

psychological support. Remember that you can also contact our helpline on 0808 800 2244 or helpline@headway.org.uk.

How can Headway help?

We offer a number of services that can be of help to you through this difficult time. These include the following:

- Our Emergency Fund can offer financial assistance to families struggling with the unexpected costs of brain injury, including travelling costs and overnight accommodation while loved ones are in hospital.

- Our nurse-led helpline is available to offer information, support and a listen-ing ear to anyone affected by brain injury, including families, partners and friends who have a loved one in a coma.

- Our online communities can be used to connect with and get advice from others in similar situations.

- Our network of support groups and branches offers local support to people affected by brain injury. Many of these will also support the families and partners of people affected by brain injury.

For further information on these and other Headway services, visit our website at www.headway.org.uk/supporting-you.

Conclusion

We recognise that this will be a very difficult time for yourself and your loved ones. Unfortunately, there are no miracle cures for PDOCs and it is not possible to predict if and when

someone will begin to recover. However, we hope that some of the information in this publication has been helpful. Finding ways to look after yourself and getting involved in your loved one's care can provide some relief, while being supported by others and accepting help where available can be beneficial.

Please remember that you can contact relevant Headway services for further information and support (see section How can Headway help?)

The next section lists other sources of support and information on this topic.

Further support and information

- The Royal College of Physicians have produced a set of guidelines for the management of PDOCs, which is available to both purchase and freely download at www.shop.rcp.ac.uk/products/prolonged-disorders-of-consciousness-following-sudden-onset-brain-injury-national-clinical-guidelines.

- Healthtalk is a website containing lots of useful information and videos from professionals and families with a loved one in a coma or PDOC state. You can visit the website at www.healthtalk.org and use the search function to find information on 'vegetative states' or 'minimally conscious states'.

- The Coma Disorders of Consciousness Research Centre is a group of researchers exploring coma and PDOCs. They also signpost families with a loved one in a coma/PDOC to sources of support and provide training to professionals. Visit their website on www.cdoc.org.uk.

- The NHS website also has information on coma/PDOCs, available at www.nhs.uk/conditions/disorders-of-consciousness.

Glossary

Advance Decision to Refuse Treatment/Living Will - a set of instructions someone can make to specify treatment they want to refuse if, in the future, they fall ill and are unable to express this themselves.

Anoxic brain injury - a brain injury caused a deprivation of oxygen to the brain.

Artificial nutrition and hydration (ANH) - nutrition and fluids that are given to someone who is unable to eat or drink by themselves.

Best interests - a way of making ethical decisions on behalf of someone who is unable to make decisions for themselves because they have lost capacity to do so.

Cognitive - relating to the thinking skills that we use to process information and learn, such as memory, making decisions, concentrating and multi-tasking.

Coma - a state of unconsciousness in which a person looks like they are asleep but they cannot be woken up, does not respond to stimuli (such as light or sound), does not voluntarily move and does not have a normal sleep-wake cycle.

Consciousness - a state of both wakefulness and awareness, in which a person's eyes are open, they are aware of both themselves and their surroundings, and they can interact with others.

Court of Protection - a UK government body that is responsible for making decisions on financial or welfare matters

for people who lack capacity to do so themselves under the framework of the Mental Capacity Act (2005).

Metabolic - relating to physical processes in the body that create energy.

Minimally conscious state - a state in which a person has minimal but present awareness of themselves and their surroundings in which they are able to interact with, although this awareness is inconsistent.

Rehabilitation - a programme of therapies designed to help people with regaining lost skills due to illness, with the aim of minimising disability.

Stimuli - plural for stimulus, something that causes a reaction in the body such as light, noise or smells.

Traumatic brain injury - an injury to the brain caused by a trauma to the head (head injury). There are many possible causes, including road traffic accidents, assaults, falls and accidents at home or at work.

Vegetative state - a state in which a person is awake but unaware, can react to stimuli (such as light or sound), and show some spontaneous behaviours, but has no awareness of themselves or of their surroundings.

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We hope that this has been a helpful resource. Please consider sharing your feedback with us by scanning the QR code or by visiting our publication feedback survey https://uk.surveymonkey.com/r/hwpublications.

Learn more and support our work at www.headway.org.uk/get-involved.

This information was last reviewed in 2024.

We're here to listen.

If you need support, or have a question about brain injury, contact our free nurse-led helpline:

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