Coma after brain injury

This publication is part of Headway's *Effects of brain injury* series. To browse through our publications on a range of issues relating to brain injury and download these free-of-charge, visit www.headway.org.uk/information-library.

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Introduction

This publication is for the families and loved ones of a patient in a coma after brain injury.

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 may also be dealing with a significant change in your circumstances and many difficult emotions.

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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.

Do feel free to contact our nurse-led helpline if you have questions or need any emotional support. The helpline team are available on 0808 800 2244 or helpline@headway.org.uk.

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

What is a coma?

In cases of serious injury to the brain, for example following a road traffic collision, a stroke or an **anoxic brain injury**, an immediate consequence can be a loss of **consciousness**. If this lasts for longer than 6 hours, the person is in a coma.

When in a coma, a person may look like they are asleep, but they cannot be woken up. They do not respond to any **stimuli**, such as touch, light or sound, nor can they make any intentional or purposeful movements. They may cough or swallow, but these are reflexive and not intentional.

Unfortunately, nobody can tell how long a coma will last for. In many cases they last for a few weeks, but this can be much shorter or longer, and will depend upon factors such as the person's age and the extent of their brain injury.

Not knowing how long a coma will last, or indeed if the person will 'wake up' at all, is one of the hardest things for families to deal with at this stage. The suggestions given further on in this publication might help you to cope in the meantime, while the remainder of the information in this document can help you to make sense of what is going on and what might happen next.

Induced coma

An induced coma is different to the type of coma that someone naturally falls into after brain injury. A person in an induced coma will have intentionally been placed into this state by clinicians at the hospital. This will be done by administering specialist medications. It will be temporary and carefully controlled.

A person will be placed into an induced coma if it will help to prevent further damage from being sustained to the brain, and to help with recovering after serious illness or injury.

The person's condition will be closely monitored throughout this process, and when they are 'woken up', this will be done very gradually by slowly reducing the medications.

A person being woken up from an induced coma may initially appear confused and distressed, and they might need to be sedated. This can be very concerning for families but be assured that it is a normal procedure. Your loved one will not be kept in the induced coma for any longer than is necessary.

Treatment during a coma

Your loved one will 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 a clinical tool such as the Glasgow Coma Scale (GCS). This is used to score someone's ability to open their eyes, move and speak. The scores range from a minimum of 3 to a maximum of 15 - a person

in a coma will usually score 8 or less on the GCS. They will be assessed regularly to check for any changes to this score.

Any decisions regarding your loved one's treatment will be made in their **best interests**. This means that while family and loved ones' 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 help 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.

Coma stimulation programme

Some people feel that presenting their loved one with familiar **stimuli** might help them to emerge from the coma - for example, playing music that they enjoy, reading to them from their favourite books, talking to them about daily events, showing them personal photographs or placing familiar objects in their hands. These activities form the basis of what is called a coma stimulation programme.

Coma stimulation programmes offer a chance to get involved in your loved one's care, but there is limited evidence for their effectiveness. However, you can still ask nursing staff about this if you think it will be a helpful way for you to get involved.

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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. 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.

- **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 below.

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 - unfortunately, no one can say this for certain, and children need to know that they can rely on what they are being told.

- **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 hospital 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*.

Possible coma outcomes

Unfortunately, it is impossible to tell if and when a person will wake up from a coma. In the early days and weeks of injury, it is really a matter of observing, waiting and hoping for the best.

If a person ‘wakes up’, it is likely that they will still need to undergo a period of continuing treatment in hospital and rehabilitation to help with regaining any skills lost from the injury. They may still need care after returning home and may experience long-term challenges as a result of the injury. Information on what happens when a person emerges from a coma is provided in the following section *Emerging from a coma.*

In cases of very severe injury, it may no longer be considered in the person’s best interests to keep them on life-sustaining treatment. This can be an incredibly distressing time for family, and it is vital that the right support and information is given to them at this stage. Further information on this is available in the section *Withdrawal of treatment* on page 9.

Emerging from a coma

The term for ‘waking up’ from a coma is ‘emerging’ from a coma.

Unfortunately, it is impossible to tell if and when a person will emerge from a coma. However, if they do emerge, they will not suddenly sit up or start asking questions, like we sometimes see in films.

In most cases, a person will emerge from their coma and begin to regain consciousness, although they will be very confused at first about where they are and what has happened.

In some cases, a person will not immediately begin to regain consciousness, but will instead progress into a **vegetative state (VS)** or a **minimally conscious state (MCS)**. These are called **prolonged disorders of consciousness (PDOC)**. In a state of PDOC, the person is no longer in a coma, but they are not yet fully alert or conscious. Further information about these states is available in our publication *Prolonged disorders of consciousness after brain injury*.

They might also behave unusually, for example they might shout, swear, try to pull hospital tubes out or behave inappropriately. This can be very upsetting for family, especially if the behaviour is out of character. Be assured however that it is a normal and temporary part of the recovery process known as post-traumatic

amnesia. Your loved one is not intentionally behaving in this way and probably will not remember their behaviour during this time. More information on this stage is available in our publication *Post-traumatic amnesia after brain injury*.

A person will then be transferred to a neurological ward, where their treatment will continue, and they may undergo a period of **rehabilitation**. More information on this stage and next steps is available in our publication *Rehabilitation after brain injury*.

Withdrawal of treatment

Unfortunately, in some cases of severe injury, continuing to treat someone in a coma 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 in hospital.

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 to talk on 0808 800 2244 or helpline@headway.org.uk.

Frequently asked questions

What does being in a coma feel like?

Upon emerging from a coma, some people describe the coma as feeling like being in a dream, and that parts of their hospital care appeared in, or took on a distorted form within the dream, such as hearing beeps of machinery or feeling their bed being moved around.

Some people report having heard the voices of their loved ones or hospital staff. Others report having no recollection of their time in the coma at all.

Experiences are varied, and ultimately it is impossible to tell how your loved one is feeling in a coma. In any case, it might be helpful for you to talk to them gently and reassuringly as if they were awake, just in case this does help.

When will my loved one wake up from the coma?

Unfortunately, it is impossible to tell if and when someone will emerge from a coma. In many cases, comas last for a few weeks, but this can be much shorter or longer, and will largely depend on the extent, type and location of injury in the brain. For instance, there is a part of the brain called the brainstem which, if severely damaged, can result in the person remaining in a coma.

How can I help my loved one to wake up from their coma?

Unfortunately, there is no proven way that you can help your loved one to wake up from their coma. However, there may be ways in which you can offer comfort to your loved one and feel involved in their care. Some people say that the voices of their loved ones provided comfort to them while they were in a coma, so talking to your loved one gently and calmly might be helpful. Talk to them in a normal voice, and do not say anything that you would not want them to hear.

My loved one moved when I touched them - were they responding to me?

While it is natural to want to hope that movement might be in response to your touch (or voice, familiar music, familiar scents, etc), it is more likely that this is reflexive rather than done with any purpose or intent.

Ask clinicians involved in your loved one's care about signs to look out for that might suggest that your loved one is beginning to emerge from their coma.

You can also discuss the option of video recording your interactions so that you can share any recorded movements with clinicians to discuss these together. Clinicians may also be able to teach you to use simple clinical measures to document your observations.

You may be spending more time at your loved one's bedside than them. You may therefore be more likely to pick up on signs if your loved one is beginning to emerge from the coma.

Will my loved one ever walk or talk again?

It is impossible to say if and when a person will emerge from a coma, and what their condition will be when they emerge, as all cases are different. In the early stages, clinicians may tell loved ones to 'prepare for the worst', or that their loved one may never walk or talk again. This can be very difficult to hear, but it is important to prepare for all eventualities.

It may be that your loved one has difficulties with walking or talking after emerging from a coma, but many people go on to making good long-term recoveries after brain injury. **Rehabilitation** can be offered to help with redeveloping these skills, and adaptive equipment can be used where needed to adjust.

People may also develop a range of physical, emotional, **cognitive** or behavioural effects after brain injury, such as having problems with their speech or thinking skills, for which varying forms of **rehabilitation** and adaptive techniques can also be offered.

Many people go on to making good recoveries and living fulfilling lives after brain injury, even after having been through a coma. The journey to recovery can be long and take a significant amount of adjustment, but at Headway we know that there can be life after brain injury.

Why is my loved one in a coma?

Our brains are responsible for everything that we think, feel, say and do. It is also responsible for our most basic functions such as breathing, being alert and regulating our sleep-wake cycles.

While the brain is naturally well protected, accidents or illnesses can cause damage, for instance through injuring specific brain structures or causing blood to leak into the brain. This can interfere with the brain's functioning, and in cases of very severe injury, can lead to a coma.

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 listening 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.

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 by 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

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 complete 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.

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.

Prolonged disorders of consciousness – a state following injury to the brain in which a person has a disordered level of consciousness for a prolonged period of time (i.e. at least 4 weeks).

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.

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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