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# Coma & impaired consciousness after brain injury

A guide for relative's and carers

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## About the guide

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### A guide for relative's and carers

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### Acknowledgements

The information booklet was written with the help of the following research group members: Professor Pickard (University of Cambridge Department of Neurosurgery), Professor David Menon (University of Cambridge Department of Anaesthesia), Professor Barbara Wilson (MRC Cognition and Brain Sciences Unit, Cambridge), David McNiven (Sue Ryder Foundation), Dr Judith Allanson (Consultant in Neurorehabilitation, Vale of Aylesbury Primary Care Trust), Dr Narinder Kapur (Department of Neuropsychology, Addenbrookes NHS Trust, Cambridge), Dr Bonnie-Kate Dewar (MRC Cognition and Brain Sciences Unit, Cambridge), Louise Elliott (Department of Physiotherapy, Addenbrookes NHS Trust, Cambridge).

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## Introduction

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This booklet is intended to provide general information about impaired levels of consciousness after brain injury. It has been written to answer some of the questions asked by relative's and carers of people with impaired consciousness.

It is important to stress that the severity of injury and resulting impairment will differ from one person to another. Therefore it is important that you also speak to the doctor and care team looking after your relative who will be in a position to offer specific advice about treatment, medication etc.

## What is consciousness?

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Consciousness is made up of two essential parts: wakefulness and awareness.

### **Wakefulness**

Wakefulness (sometimes called arousal), is the ability to open your eyes and to have automatic responses (reflexes) such as coughing, swallowing and sucking.

### **Awareness**

Awareness represents a range of abilities – at the lowest level it might reflect concentrating with your eyes upon an object or visually following someone move past your bed – at the highest level it represents your ability to remember something, communicate, plan and imagine things.

It is important to stress that, as far as we know, wakefulness can occur without awareness, but awareness cannot occur without wakefulness. The brain systems controlling wakefulness are largely different to those which control awareness.

## How is consciousness impaired after brain injury?

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Consciousness is maintained by lots of different structures and connections in the brain. When someone injures their brain some of these structures or connections can be damaged.

### **Axons**

Axons are essentially wires or cables, which allow different parts of the brain to communicate with one another. Unfortunately, when someone has a serious accident some of these wires can become damaged or broken preventing different parts of the brain from communicating. This has an effect on someone's level of consciousness.

### **The thalamus**

The thalamus (see figure 1) is very important for maintaining wakefulness or arousal. Essentially, it acts like a telephone exchange, receiving information from the outside world and sending it off to other parts of the brain, which are interested in that information. Unfortunately, this structure is often damaged when someone hurts their brain. Hence, information from the outside world, which in turn stimula-

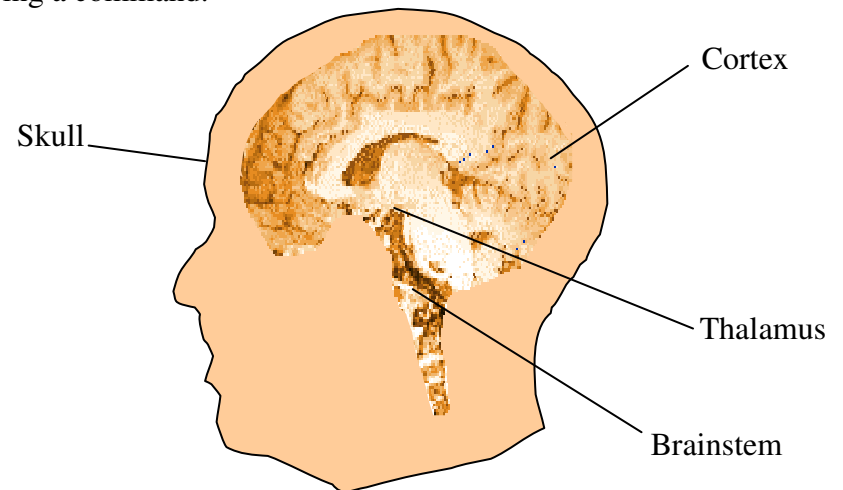
## How is consciousness impaired after brain injury?

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tes arousal, cannot be passed to other areas of the brain, thus impairing consciousness

### **The cortex**

The cortex (see figure 1) plays a vital part in maintaining awareness. It is essentially the clever bit of the brain that does all the calculations and works out a response. Due to its proximity to the skull (see figure 1) it can be damaged when someone hits their head, thus affecting its ability to carry out complex processes, such as remembering something or obeying a command.



**Figure 1.** Picture of the human brain

## What causes the impairment?

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Damage to axons, the thalamus and parts of the cortex can be due to a lot of different events. The brain floats within the skull as a jelly type sponge suspended in a pool of fluid. When someone hits their head very hard the brain will shake back and forward inside the skull. Unfortunately different parts of the brain move back and forward at different speeds to other parts of the brain. Hence, a lot of pressure is put on the wiring or axons and sometimes these are stretched or even broken.

Damage is also caused by the impact of hitting an object and this might fracture the skull and damage areas of the brain directly beneath. Similarly, the inside surface of the skull is rather rough, so as the cortex moves back and forth it can be damaged by the rough inside of the skull.

When someone has a stroke or a bleed inside the brain, the blood supply can be cut off from certain parts of the brain starving them of oxygen. Furthermore, because the skull is a solid structure a bleed causes an increase in pressure within the brain. This is because blood takes up

## What causes the impairment?

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space, thus squashing the brain. This is also the case when the brain swells due to bruising – the brain tissue gets bigger but the space it can occupy is the same size. Hence the wiring of the brain can become stretched and the blood supply reduced. Damage to the brain can happen in many other ways. For example, if you stop breathing your brain is starved of oxygen, or if you incur a serious infection, such as meningitis, areas of your brain may be damaged thus reducing your level of consciousness.

It is important to stress that the injury and nature of subsequent impairment will vary from person to person. Your doctors will be able to provide information specific to your relative.

## How is the diagnosis made?

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The diagnosis of impaired consciousness is usually made following extensive testing by at least two independent doctors supported by the observations of other health care professionals. Depending upon the level of impairment your relative displays, the doctors will use one of four classifications:

### **Coma**

The term comatose is used to describe a non-sedated person who shows no signs of wakefulness or awareness of themselves or the environment. Comatose patients lie with their eyes closed and they do not respond to command. Coma persists for at least one hour and may last between two and four weeks during which time the person may awaken or subsequently progress to the vegetative or minimally conscious state.

### **Vegetative state**

The term vegetative state is used to describe someone who is awake but unaware of themselves or their environment. A person in a vegetative state will open their eyes, demonstrate sleep-wake cycles and basic

## How is the diagnosis made?

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reflexes, such as blinking when they are startled by a loud noise. However, they do not demonstrate any purposeful response to sensory or cognitive stimuli, such as following an object with their eyes or responding to command.

### **Minimally conscious state**

The term minimally conscious state describes a person who shows intermittent but clear evidence of awareness of themselves or their environment. This classification is given if they can respond to command; for example, moving a finger reliably when asked to do so.

### **Locked-in syndrome**

This term is used when someone has had a specific type of injury resulting in damage to the brainstem (see figure 1). Someone who is locked-in is both awake and aware, but they are unable to respond because they are paralysed and unable to speak. Typically, persons in this condition are able to communicate only by up and down eye movement.

### **Initial hospital treatment**

Immediately after a brain injury, the medical team's priority is to get the person stable and to breathe for themselves. Depending upon the type of injury and the facilities at your local hospital, your relative may be transferred to a different hospital for treatment. This tends to happen when someone is admitted to a small local hospital without intensive care facilities.

Once your relative is stable they will soon be in a position to leave the intensive care unit and go to a general ward, where work to assist the recovery of your relative will continue. They may stay in the ward for some time, or they may be transferred back to your local hospital or to a rehabilitation centre.

The type of treatment your relative receives will largely depend on what sort of injury they had. However, in addition to the medical staff and nurses, your relative may see physiotherapists, occupational therapists, speech and language therapists, psychologists and sometimes researchers.

### **How long will recovery take?**

This is impossible to predict - recovery depends a lot on the severity of the injury. In some people recovery may be very slow and continue over several years, whilst in others this might be very quick. Unfortunately, however, some people do not fully regain consciousness and remain in a vegetative or minimally conscious state for many years.

### **What can be done to help recovery?**

The medical team treating your relative will primarily work to ensure that your relative is given the best opportunity for natural recovery to take place. This will involve preventing further complications such as infections and pressure sores. Other rehabilitation staff will work to ensure your relative's range of movement in their arms and legs is maintained. In some care centres other kinds of treatment may be offered to help recovery, however, there is no proven treatment that works for everyone. The most commonly performed treatment is sensory stimulation.

## Sensory stimulation

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Sensory stimulation involves stimulating the senses (vision, hearing, taste, touch, smell etc). This is often performed by a trained therapist, but family members and friends are encouraged to become involved. The procedure varies from hospital to hospital, so it is best to discuss this with your doctor. However, it is generally accepted that a short period of time spent each day providing this stimulation is a positive activity. Visual stimulation could involve seeing a familiar person, looking at photos of friends and family, or watching a favourite film. Auditory stimulation could involve just talking to your relative, or listening to a favorite song. Holding your relative's hand, or stroking the skin with different fabrics or objects can be helpful. Smelling a favourite perfume or the scent of flowers (depending upon known allergies) may be stimulatory. Taste is more difficult to stimulate and should only be done after consulting with your relative's doctor. This is because some people are unable to swallow or eat after a brain injury and are instead fed through a tube in their stomach. In some cases, it is advisable not to talk about food in front of someone unable to eat for themselves.

## Sensory stimulation

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### **Remember**

Someone who has had a brain injury may have a short attention span and tire very quickly. Thus your doctor or therapist may only perform this type of stimulation for short periods at a time. They may also try to regulate the amount of stimulation your relative receives. This could involve limiting the amount of television they watch or trying to reduce the amount of surrounding noise on the ward.

## Physiotherapy

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In addition to stimulating the senses, a physiotherapist will work to maintain and improve the condition and range of movement in your relative's limbs, neck and spine. This is very important as the condition of muscles and joints can deteriorate very quickly after a brain injury. To combat this you may see your relative wearing special splints. The physiotherapist may also perform special procedures such as standing your relative using a special bed or harness.

### **What can I do to help?**

You can also help maintain and improve the condition of your relative's limbs. However, it is very important that you receive advice and training from your relative's physiotherapist before doing this. Remember, a stretch performed incorrectly could actually harm your relative rather than help, so it is very important to get appropriate advice and training.

A simple way you can help is to massage your relative's hands and arms, legs and feet. You can use a body lotion or oil if you wish and it will help keep their muscles supple and their skin in good condition.

## Long-term care and outcome

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Once your relative is stable, your doctor may discuss transferring them to a hospital closer to home or a specialist rehabilitation or care home. This is often to make visiting easier for friends and relative's – an important part of rehabilitation - but also to ensure that your relative is in a place where they can be comfortably treated and cared for. It is the aim of these centres to get your relative to a stage of recovery where they can return home. However, in some cases long-term residence in a care home or rehabilitation centre may be required to meet their needs.

### **Outcome**

Persons with impaired consciousness after a brain injury may not fully recover consciousness depending upon the severity of their initial injury and how well their brain has repaired itself over the months or years after the injury. In some cases a person may not recover any awareness of themselves or the environment, while in others they may be intermittently aware but physically disabled. Planning for the future in these circumstances can be very difficult. However, there are sources of support and advice available (see page 20).

## Withdrawing nutrition and hydration

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It is a very sad fact that due to the severity of some people's injuries they will never recover consciousness nor survive without machines providing nutrition and hydration. Where this is the case, you may have to endure the extremely emotional and stressful process of deciding whether to continue or to withdraw treatment. In England and Wales this decision requires approval from a Court of Law, whereas in Scotland the decision is made by the family and the medical team. In both situations, the decision to continue or withdraw treatment is made after lengthy and detailed discussions between the patient's family, friends, lawyers and the medical team. This is a very emotional and stressful experience for everyone involved, including the medical team. Everyone varies in how they cope with this decision making process but there are trained personnel within hospitals and also nationally (see page 20) that are there to help you and to explain the process in more detail.

It is important to stress that withdrawal of treatment is not usually considered until the injured person has been thoroughly assessed and all treatment options tried to give them the best possible opportunity for recovery. Decisions to withdraw treatment are therefore rarely considered within the first 12 months following injury.

## Research

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Research into the conditions described in this booklet is taking place in the United Kingdom and abroad. Researchers are trying to understand more about the events that cause these conditions; they are also trying to develop better diagnostic tests and also to develop treatments to facilitate recovery. If you are approached by a researcher, please take time to read their information sheet explaining their work. Due to strict laws in this country, they can only study your relative with your permission and they have to keep all the information they collect secure and confidential. Regardless of the research project, the researcher will provide you with detailed information and answer any of your questions. They will also tell you that their research is unlikely to help your relative directly, but may help others in a similar situation in the future. Because participation in a research project is voluntary you can withdraw your assent at any time without giving an explanation.

## Summary

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Unfortunately, only a small number of people who enter a vegetative or minimally conscious state following brain injury make a full recovery. Sadly, due to the severity of the injury the vast majority remain disabled. Recovery may be slow and limited to certain skills and this may occur over months or even years. Family members and friends can play a vital role in helping the recovery process and there are many opportunities for you to help.

## Sources of support and advice

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### **Brain and Spine Helpline**

**0808 808 1000**

Brain and Spine Foundation

7 Winchester House

Kennington Park

Cranmer Road

London SW9 6EJ

<http://www.brainandspine.org.uk>

(Information and support on neurological conditions for patients, carers and health professionals)

### **Headway (National Head Injuries Association)**

**0808 800 2244**

4 King Edward Court

King Edward Street

Nottingham

NG1 1EW

<http://www.headway.org.uk/>

(Support for people with head injuries and their families)