

Acquired Brain Injury and Intensive Care

Acquired brain injury (ABI) means an injury that has happened to the brain.

This information sheet is for patients and relatives and will explain about having treatment in the Intensive Care Unit (ICU) for ABI.



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Introduction

Each year about 350,000 people are admitted to hospital in the UK with an acquired brain injury. 95% of these admissions are for minor injuries, but 5% are for moderate or severe injuries.

This can be an extremely difficult and distressing time for patients and their families. It is very important that you receive as much information and support as possible to help you during this time.

What is Acquired Brain Injury (ABI)?

Acquired Brain Injury is any injury that has happened to your brain since birth. This can happen by:

- your head being hit. This is known as a Traumatic Brain Injury (TBI) and can be caused by a road accident, a fall or a strike to the head. There are two main types of Traumatic Brain Injuries, which are called closed injuries and penetrating injuries. In a closed injury an object doesn't directly go into the brain but the brain is injured by being banged and shaken around inside the skull. This can cause widespread damage, even on the opposite side of the brain to where it was hit. A penetrating injury means an object goes through the skull and into the brain and causes an injury only in this specific part of the brain.
- a stroke, which happens when the blood supply in the brain is blocked or when a blood vessel in the brain bursts.
- an infection (such as meningitis or encephalitis) that can cause the brain, or the membranes that surround it, to swell.
- a brain tumour. This is an abnormal growth of cells in the brain that can damage the tissue around it.
- a lack of oxygen to the brain. This is called a 'hypoxic injury' and it can happen when not enough oxygen gets to the brain, for example from a heart attack, nearly drowning or carbon monoxide poisoning.

After this first injury, the brain can be affected by other problems and these are called secondary injuries. Normally our brain fits closely within our skull but after

an injury, our brain swells and there is not space for this swelling. This can cause pressure within our brain and means other areas are squashed, which can affect the blood flow around the brain.

There are other causes of pressure to the brain as well, such as swelling of the brain (known as cerebral oedema) and bleeding or clots (called haemorrhages and haematomas). There can also be damage to brain cells or too much cerebrospinal fluid around the brain (which is called hydrocephalus).

Brain injuries can affect any area of a person's brain and this means that anything can be affected, such as:

- how our bodies work (physical skills)
- how we think, learn and remember (cognitive skills)
- how we feel and act (emotional and behavioural skills).

Information for patients

Arriving at hospital

You will probably have been taken to hospital by ambulance, and doctors in the Emergency Department (ED) will have looked at your injuries and decided on the best treatment for you.

To help doctors identify what brain injuries you had, you will probably have had scans such as a CT or MRI scan. A CT scan is a special type of X-ray test. CT stands for computerised tomography. MRI stands for Magnetic Resonance Imaging and it gives more detailed information than the CT scan.

These scans can help to show the brain and any bleeding or blood clots. These scans will identify what treatment you need. They cannot tell doctors how completely you will recover from your injuries.

The Neurosurgical Unit

You may have needed to be transferred to a neurosurgical unit, which is a ward with specialist knowledge about treating brain injuries. The Neurosurgeon and their team will have assessed your injuries in more detail and continued your treatment.

Sometimes the neurosurgical unit may be at a different hospital and you may have been transferred by ambulance to enable you to get the special treatment you needed.

“Brain surgery is a very delicate procedure which can take many hours to do.”

Surgery

You may have needed surgery if your scans showed that you had a blood clot, a pooling of blood or fluid on the brain, or a wound that went through the skull into your brain. Brain surgery is a very delicate procedure which can take many hours to do.

Intensive Care Unit

After surgery, you will have been taken to the Critical Care Unit, Intensive Care Unit (ICU) or High Dependency Unit. This section will talk about Intensive Care as a general term meaning any of these units.

Intensive Care is where the patients who need a special type of care in a hospital are treated and looked after. The main aim of Intensive Care for brain injury patients is to reduce the risk of any further damage to your brain and to let the bruising and swelling go down to help your brain and body begin to recover.

There are a number of specialist Neurosciences Intensive Care Units in the country which have specialist staff and equipment to treat people with brain injuries. A person with a brain injury will usually go to one of these units but this is not always possible.

In Intensive Care:

- each nurse will look after one or two patients, so you can be carefully watched 24 hours a day. Your pulse, blood pressure, breathing, oxygen levels and how much liquid you take in and urine you pass is looked at all the time. This is all important because staff can see how you are and change your treatment as needed.
- staff can give you specialist treatments for injuries to other parts of the body, such as broken bones or damage to other organs, such as the heart and lungs.
- there are highly trained doctors, nurses and physiotherapists and other healthcare professionals who will look after you. They will also help your relatives by explaining what is happening and what treatment you are having.
- you may have a special tube inserted into your head to help staff monitor the pressure in your brain. This is called an Intracranial Pressure Monitor and it will only leave a small scar under your hair once it is removed.
- you may have a catheter. This is a tube which is put into your bladder to allow urine to be collected and measured.
- you may be fed by a drip or a tube that either goes through your nose into your stomach (nasogastric tube) or directly into your stomach (called a gastrostomy tube).
- you can have breathing support if you need it. At first, you may have had a breathing tube down your throat. If you needed help breathing for some time, you will have had a tracheostomy. This is where a small hole is made in the front of your neck so that a breathing tube can be put into it and attached to a ventilator (a machine to help you breathe).

Early rehabilitation

Rehabilitation means exercises to start your recovery. Physiotherapists will have started to work with you in ICU, even if you were unconscious. This is to make sure that other problems do not develop (such as chest infections, muscle tightness or pressure sores) from being in one position too long.

Once you were conscious, the physiotherapists will have worked with you to do exercises in bed, then you may have been well enough to do exercise in a chair and standing up. Even sitting up can feel difficult at first if you have been lying down for a long time, and so sitting may have formed part of your exercise routine.

Brain injury can cause many difficulties which require rehabilitation. For example, a speech and language therapist may have helped you with communication or if you found it difficult to swallow. You may have needed to practise improving your speech and your memory. Talking to family and friends about everyday things will have helped this. You may have got tired very quickly in your early recovery and even simple tasks (such as talking) may have felt difficult.

Leaving ICU

Sometimes it can feel frightening to leave the Intensive Care Unit to go to a general ward. These changes are happening because you are getting better, but it can be a difficult time for you and your relatives because there is no longer the one-to-one nursing that you had in Intensive Care, but you still do not feel well. Some hospitals have an Outreach Team that will come to visit you once you

Outreach teams can help to answer any questions or worries that you have

have left ICU. They will see how you are and can help to answer any questions or worries that you have.

You may have many questions about what happened to you, and it is likely that you will be unable to remember everything that has gone on. Some hospitals organise patient diaries and it

may help to read this when you feel strong enough to try and piece together what happened. If you didn't get one, you can ask your family to write down a brief summary of what happened while you were in the ICU so you can begin to make sense of what happened.

Once you leave the ICU, your medical team will advise you on what exercises to do that will help you get stronger. You will need to take things very gently, building up

activity slowly (for example increase the time you spend sitting from 10 minutes, to 20 minutes and so on) and resting when you need to. Try not to get frustrated at the things you can't do and it can be helpful to write down what you do each day, to help you remember how much progress you have made.

Please see the 'Further information' section on p13 for more about what might help during your recovery.

Information for relatives

Having your relative in the Intensive Care Unit with a brain injury can be a very worrying time for you and your family. It is normal to feel desperate to know everything you can about what will happen and their chances of recovery. The staff will let you know what treatment they are giving to the patient and will answer your questions the best they can. They may not be able to tell you at this stage if the patient will make a full recovery and sometimes all that can be done is to wait to see how the patient responds to treatment.

If you have questions that can't be answered by the nursing staff, you can make an appointment to talk to the consultant in charge of your relative's care. Before you meet, write down any questions you have. It might be helpful to have a friend/relative with you during the meeting so they can remind you afterwards what was said because it can be hard to take in information when you are worried or upset.

Coma

It is common after brain injury for people to lose consciousness. This can happen for a short time or last for many weeks. There are different levels of coma, from a shallow one where the person will respond to pain or if someone talks to them, to a very deep coma where the person shows no response at all.

It is impossible to tell how long a coma may last. It is generally a good sign for long-term recovery the sooner someone comes out of a coma, but brain injuries do

vary and it is very difficult to make predictions how people might recover.

Coming out of coma can be a slow process. The brain needs to slowly adjust to the information it is receiving (it gets this information from what a person is seeing, hearing, feeling etc) and work out how to process it. When patients first come out of a coma, they may only be able to open their eyes, or respond to touch or speech. Gradual improvement will usually then take place.

Sedation / Induced coma

While in ICU, your relative may be put into an 'induced coma'. This means they are sedated (given strong drugs to keep them asleep) to reduce any swelling on the brain. The length of time spent in an induced coma does not give information about what type of recovery the patient will make.

Talking to a patient in a coma / induced coma

Your relative may be aware of being touched, or hearing your voice, even though they may show no sign of it. Do hold their hand, talk to them and tell them they are in hospital. It can be difficult to know what to say, but you can tell them news about the family, or talk about things you have done together. You could try reading a newspaper or a book to them if you don't know what to say to them, as they may find it comforting to hear your voice.

“Do hold their hand, talk to them and tell them they are in hospital”

Minimally Conscious State

Patients who have a minimally conscious state show some signs that they have awareness and may be able to respond in a small way for short amounts of time, such as answering simple questions with a 'yes' or 'no', or reaching to get something.

Vegetative State

A small number of people sustain a brain injury so severe that, although they emerge from a coma and have sleep-wake cycles, they seem to have no conscious awareness of themselves or their surroundings. If this condition persists for more than four weeks they can be classified as being in a Continuing Vegetative State. If it continues for 12 months after traumatic brain injury or 6 months after non-traumatic brain injury, they are diagnosed as being in a Permanent Vegetative State.

Minimally Conscious State and Vegetative State are very rare conditions, but they are very distressing for the patient's friends and family. Headway's website and helpline can offer help and advice.

To find out more about other families' experiences, you can visit HealthTalk.org www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/topics

Post-Traumatic Amnesia (PTA)

After a coma, patients can sometimes seem different to how they usually are, and this may be because of Post-Traumatic Amnesia (PTA). The brain is trying to make sense of what is happening and patients may not be able to remember things or make sense of day-to-day events.

Patients who have PTA may:

- not recognise friends and family or have no memory of their past
- talk in a way that doesn't make sense
- not remember conversations
- ask for people who they have not seen for many years or who have died
- be disorientated – they may not know the day or time, or not know where they are
- be confused, agitated, distressed, anxious or frightened

- show uncharacteristic/disinhibited behaviour – such as shouting, swearing, hitting out at people, inappropriate sexual behaviour, taking their clothes off or being very quiet and childlike
- trying to get out of bed and take all their drips and lines out.

ICU delirium can also cause some of this behaviour – see the ICUsteps information sheet on ‘Delirium and Intensive Care’ www.icusteps.org for further information.

Seeing your relative acting in a way that is so different from their normal behaviour can be very upsetting, especially if the person is behaving in an embarrassing or aggressive way. It is not their fault and they are not doing it to upset you but it can feel worrying to see them like this.

PTA is a stage of recovery that the patient can go through after an injury. It can last anything from a few minutes, to many weeks or months, but it will pass in time.

What can I do to help while my relative has PTA?

- Try and stay as calm as possible – if the patient sees you are upset, it might agitate them further because they don’t understand they are acting differently to normal
- Speak to hospital staff about the best way for you to manage while your relative is acting in this way
- If there is too much noise or activity around your relative who has PTA, it can make them more distressed. Where possible, a calm, quiet environment is best for them.
- Your relative may ask the same thing over and over again, which is very tiring for you. They may think something is happening that is not real. Try not to get frustrated with them or argue them out of it, as this will upset you and your relative. Try and respond calmly
- Give yourself time away from your relative so that you don’t get too tired at this time. You may find it helpful to not stay too long when you visit if you are finding it very upsetting, and share the visiting among family and friends

Remember that your relative doesn't understand what is happening to them, or why they are acting in this way. Gradually, they will begin to make sense of the world around them again, and either will not remember this time, or have patchy memories that will make it feel like a bad dream.

For more information, see Headway's factsheet on Post-Traumatic Amnesia
www.headway.org.uk/information-library

Seizures

A seizure is when there is a sudden random electrical activity in the brain. This can mean a change in or loss of consciousness, severe shaking or tongue biting.

It is common to suffer from a seizure after an injury to the brain, and staff will be watching for this to make sure that necessary treatment can be given. It can be very frightening for patients and relatives when these seizures happen, but the staff will know what to do to help the patient.

Having seizures after a head injury does not mean that your relative has developed epilepsy, your relative may be given a drug to reduce the chance of seizures happening in the future.

What may help you while your relative is in the ICU?

- Try and take one day at a time and don't look too far ahead or worry about what might happen in the future.
- Your main concern is your relative, but one way to help them is to look after yourself too. You don't have to be by their bedside 24 hours a day, and the staff will call you if there is any change in their condition, so take time to have regular meals and to sleep.
- Ask family and friends to help and support you – many people will be glad to be able to do something practical to help, whether it's cooking a meal, or taking you

to the hospital, or visiting the patient so you can have a break for a day.

- Keep a diary – make short notes each day about the patient’s condition and anything significant happening in the family. This means you can look back to see where there have been small improvements and where progress has been made. The patient may later find this diary very useful too because they may not have any memory of their time in ICU, or may have confused memories.
- If you need advice or support, or have questions that aren’t being answered, you can contact the Patient Advice and Liaison Service (PALS) at your hospital – ask at the reception desk about how to contact them.
- Ask one member of the family to be the main contact for other friends and family to ask about how the patient is, so that you don’t have to make lots of phone calls when you get home. Alternatively ask them to send out regular email updates to keep people informed.
- You may have a reaction to the stress you are under, either now or in the future, so if this happens, ask your GP for help or to refer you for counselling.
- Contact Headway, which has a variety of services that can help you at this time, including Headway Acute Trauma Support (HATS) nurses to support families with relatives in hospital (see below for further details).
- Headway offer a website that is a safe, secure and private online space for family members and friends to put updates on how their relative is, so they do not need to make lots of phone calls each day. Visit www.callingabout.org.uk for more information.

More information

Dealing with the after effects of a head injury for patients and relatives is a long process – you have had a very difficult and worrying time and it will take time for you all to recover from it. You will need support from your family and friends to help you get through this time, and there are organisations that can help you. Visit www.icusteps.org/patients/contacts for more information.

ICUsteps

ICUsteps website contains information to help intensive care patients and their relatives, including a booklet about intensive care and returning home after ICU called 'Intensive Care: a guide for patients and relatives' and patient and relative accounts of their time in ICU. Visit www.icusteps.org

Headway – the brain injury association

Headway – the brain injury association is a charity which gives help and support to people affected by brain injury.

The contact details for Headway are:

Freephone helpline: 0808 800 2244 (Monday–Friday, 9am–5pm)

Telephone: 0115 924 0800

Website: www.headway.org.uk

Fax: 0115 958 4446

Email: helpline@headway.org.uk

Headway offer many services to those affected by brain injuries, including:

- Local Groups: A network of over 120 local Headway Groups throughout the UK offers a wide range of services including rehabilitation programmes, carer support, social re-integration, community outreach and respite care
- The Headway helpline provides information, signposts to sources of support and rehabilitation services, and offers a listening ear to those experiencing problems
- Headway Acute Trauma Support (HATS) Nurses. HATS Nurses support family members and carers of people in the early stages following an acquired brain injury. They provide a listening ear, emotional and practical support, information and advice. The service is particularly for those with relatives in Intensive Care Units. Visit www.headway.org.uk/supporting-you/headway-acute-trauma-support for more information
- Information on many aspects of brain injury and its effects. This information is available free of charge, visit www.headway.org.uk/information-library or call Freephone helpline 0808 800 2244
- Providing grants from Headways Emergency Fund for families coping with financial difficulties.

HealthTalk.org

This website provides information on a wide variety of personal experiences of health and illness. These include Family experiences of Vegetative and Minimally Conscious States, featuring over 250 clips from in-depth interviews.

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Our information and general advice is based on experiences of former ICU patients and it should not replace the advice you receive from healthcare professionals. ICUsteps cannot accept responsibility or liability from the use of this resource. ICUsteps is a patient-led support charity. For more information, resources or to make a donation, visit our website: [icusteps.org](https://www.icusteps.org)