Introduction

Each year as many as 170,000 people are admitted to hospital in the UK with a head injury. Of these, 10,000 – 20,000 sustain a brain injury requiring treatment in ICU.

This can be an extremely difficult and distressing time for patients and their families. It is very important that family members receive as much information and support as possible to help them understand and cope with the situation.

This factsheet contains information for patients and relatives that might be useful while the patient is in ICU.
What is brain injury?

This factsheet is about acquired brain injury (ABI) which means 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 an assault. TBIs come under two main types called closed injuries and penetrating injuries:
  - In a closed injury an object doesn’t directly go into the brain. Instead, 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 the impact.
  - A penetrating injury means an object goes through the skull and into the brain and causes an injury only in a specific part of the brain.
- a stroke, which happens when either the blood supply in the brain is blocked or when a blood vessel in the brain bursts.
- an infection, such as meningitis or encephalitis, which can cause the brain or the membranes that surround it, to swell.
- a brain tumour – an abnormal growth of cells in the brain which can damage tissue around it.
- A lack of oxygen to the brain (hypoxic injury) which can happen as a result of a heart attack, near drowning, carbon monoxide poisoning etc.

There can be further complications after the initial problem, which 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 causes areas to be squashed, which can affect the blood flow to the brain. There are other causes of pressure to the brain such as too much fluid on the brain (known as cerebral oedema), bleeding or clots (haemorrhages and haematomas). Further problems include damage to the cells, too much cerebrospinal fluid in the brain (which is called hydrocephalus), a fall in blood pressure and finding it difficult to breath (respiratory failure).

Brain injuries can affect any area of a person’s brain and this means that anything can be affected:

- physical – how our bodies works
- cognitive – how we think, learn and remember
- emotional and behavioural – how we feel and act.
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. These can show the brain and any bleeding or blood clots. These scans will identify what treatment you need, but 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 surgical team will have assessed your injuries in more detail, continued your treatment and will have operated on you if necessary.

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

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 that can take many hours to do.

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

Intensive Care is where the most ill patients in a hospital are treated and nursed. The main aim of Intensive Care for head 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. Ideally, a brain injured person will go to one of these units but that is not always possible.

In Intensive Care:

- you can be carefully watched 24 hours a day - so 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 who will look after you. They will also help your relatives by explaining what is happening and what treatment you are having.
- nurses look after fewer patients, so each nurse will look after only one or two patients. This means you can be closely monitored at all times.
- 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 (ICP) 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 PEG or 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 attached to a ventilator can be put into it.

**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 worked with you to do exercises in bed, then may have progressed to chair and standing exercises. Even sitting up or sitting in a chair can feel difficult at first if you have been lying down for a long time, and this 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 swallowing difficulties. You may have needed to practise
improving your speech and memory and 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 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 ICU so you can begin to make sense of your experience.

Once you leave ICU, 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 remember how much progress you have made.

Please see the ‘Further information’ section for more about what might help during your recovery.
Information for relatives

Having a relative in Intensive Care with a brain injury is a very worrying time. 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 vary from lasting a few seconds to 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 (through 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 then take place.

Sedation / Induced coma

While in ICU, your relative may be put into an ‘induced coma’. This means they are given strong drugs to keep them asleep to help reduce any swelling on the brain. The length of time spent in an induced coma is not an indication of long-term recovery.
Talking to a patient in a coma / induced coma

The patient 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 as they may find it comforting to hear your voice.

Persistent Vegetative State (PVS)

A small number of people sustain an injury severe enough to cause complete lack of awareness or ability to communicate, although they can still breathe for themselves. If this lasts more than one month, it is known as a persistent vegetative state (PVS).

Post-traumatic Amnesia

When a person has emerged from a coma they can act in an unusual way, which is called post-traumatic amnesia (PTA). The brain is trying to make sense of what is happening and patients are usually unable to remember things or make sense of day-to-day events.

Patients who have PTA may:

- not recognise friends and family or have any memory of their past
- talk in a way that doesn’t makes 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, 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, and
- trying to get out of bed and take all their drips and lines out.

ICU delirium can also cause some of this behaviour – please see the ICUsteps factsheet 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 distressing, especially if the person is behaving in an embarrassing or aggressive way. Remember, it is not their fault or anything personal against you.

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 distressed, 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.
- Your relative may ask the same thing over and over again, which is very wearing 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 distress you and the patient. Try and respond calmly.
- If there is too much noise or activity around a patient with PTA, it can make them more distressed. Where possible, a calm, quiet environment is best for them.
- Give yourself time away from the patient 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 close 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.

Fits

It is common to suffer from a fit (an epileptic seizure) after an injury to the brain, and staff will be watching for this to ensure that necessary treatment can be given. It can be frightening for relatives when these fits happen but the staff will know what to do to help the patient.

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

What may help you?

- 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 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, including Headway Acute Trauma Support (HATS) nurses to support families with relatives in hospital with brain injuries (see below for further details).
Further information for patients and relatives

**Headway – the brain injury association services**

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 it. You will need support from your family and friends to help you get through this time, and there are organisations that can also assist you, such as Headway – the brain injury association which is a charity set up to give help and support to people affected by brain injury.

Freephone helpline: 0808 800 2244 (Monday–Friday, 9am–5pm)
Telephone: 0115 924 0800
Website: [www.headway.org.uk](http://www.headway.org.uk)
Fax: 0115 958 4446
Email: helpline@headway.org.uk

A network of local Headway Groups and Branches 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**

Headway Acute Trauma Support (HATS) Nurses in the North West and West Midlands 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 in Critical Care or High Dependency Units.

HATS Nurse in the North West:

HATS Nurse in the West Midlands:

Other services provided by Headway include:

- Supporting and developing local Groups and Branches
- Promoting understanding of brain injury and its effects
- An award-winning range of publications on aspects of brain injury
- Accreditation of UK brain injury residential care providers through the Approved Provider scheme
- A comprehensive, award-winning website
• Campaigning for measures that will reduce the incidence of brain injury
• Providing grants from our Emergency Fund for families coping with financial difficulties

Headway booklets of particular relevance to the information in this factsheet include:
• Caring for someone with a brain injury
• The effects of brain injury and how to help
• Hospital treatment and early recovery after brain injury
• Redeveloping skills after brain injury
• Rehabilitation after brain injury
• Managing anger after brain injury
• Managing fatigue after brain injury
• Memory problems after brain injury
• Psychological effects of brain injury.

Headway factsheets of particular relevance to the information in this factsheet include:
• Coma after brain injury
• Coma stimulation: suggested activities
• Coping with memory problems after brain injury: practical strategies
• Dysphagia after brain injury
• Hormonal imbalances after brain injury
• Hypoxic and anoxic brain injury
• Loss of taste and smell after brain injury
• Post-traumatic amnesia

Booklets are available to buy at www.headway.org.uk/shop.aspx and some copies are available free for helpline callers. Free, downloadable factsheets are also available at www.headway.org.uk/factsheets.aspx.

ICUsteps - the intensive care patient support charity

ICUsteps is a charity set up by former intensive care patients and their family members in partnership with medical staff. We aim to promote better support and rehabilitation after a critical illness.

Our 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. There are also other factsheets including one on ICU Delirium and on Physiotherapy and Rehabilitation.

Website: www.icusteps.org
Acknowledgements

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