Hospital treatment and early recovery after brain injury



This publication is part of Headway's *About the brain* 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.

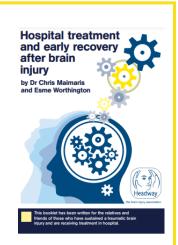
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People directly affected by brain injury can receive limited free copies of Headway print booklets by contacting the helpline on 0808 800 2244.

*print copy may contain minor differences due to revision of content



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Introduction

This publication is intended mainly for the relatives and friends of those who have sustained a traumatic brain injury (TBI) and are receiving treatment in hospital. It tells you about the immediate consequences of TBI, including how the brain is affected, what it means to be in a coma and the ways in which the person may begin to recover afterwards.

The time immediately after the injury is bound to be full of worry and uncertainty for everyone concerned. It is very important that you receive as much support and information as possible and you can ask the nurses and consultants any questions that you have. However, they are often very busy and may not have as much time to talk to you as you would like. If you have concerns about this, ask at reception to speak to the Patient Advice and Liaison Service (PALS), which is a source of advice and support.

You will probably want definite answers in the early stages, which the medical staff often can't provide. Rest assured that if this is the case, you are not being deliberately kept in the dark. If the injury is very severe then stabilising and managing your relative's condition will be the main priority. The long-term difficulties will only become apparent at a later stage, such as when rehabilitation starts, or even when they return home.

Information and knowledge about brain injury and hospital systems can help you to cope with the situation and maintain a sense of control. Reading this publication is a good start.

Please remember that you contact our nurse-led helpline for information, support and a listening ear at any stage of brain injury. The helpline is open to relatives and loved ones of a person with brain injury, as well as the person themselves. Call our helpline on 0808 800 2244 (Monday - Friday, 9am - 5pm) or email helpline@headway.org.uk.

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Traumatic brain injury: how the brain is injured

Most traumatic brain injuries occur because the head is suddenly forced to stop or start moving suddenly. These are known as acceleration or deceleration injuries. Being involved in a vehicle collision, being hit from behind while stopped at traffic lights, or a heavy blow to the jaw are all examples of this. As the brain is forced to follow the movements of the head, it is pulled out of shape and the nerve fibres, as well as the arteries and veins that run through it, are torn. Injury of this sort is usually widespread throughout the brain, although some areas can be affected more than others.

If there is a local injury to the brain, for example if a weapon is used during an assault, or the head hits against the sharp edge of a kerb, the skull can be broken and the brain injured directly. This type of injury often affects only a relatively small area of the brain and, although it can have serious results, may cause fewer problems than a more widespread injury.

In many cases, particularly road traffic collisions, the brain is injured more than once. For example, the person may first sustain an acceleration injury when they are thrown from the car and then a local injury when they land and hit their head on the road. The person may also become trapped in the car and if they cannot breathe properly or they are bleeding uncontrollably, their brain can become starved of oxygen. Lack of oxygen to the brain is known as cerebral hypoxia or anoxia.

Effects on the brain following injury

Normally the brain fits closely inside the skull, with only a little room to spare. After injury, the brain swells up and takes up more of this space. If the swelling continues, the pressure inside the skull (the intracranial pressure) rises and the brain becomes compressed. If the pressure continues rising, the arteries of the brain are squeezed shut and the blood supply to the brain is affected.

A common cause of brain swelling is the accumulation of fluid in the injured brain, known as brain oedema. Another cause of increased intracranial pressure is a

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leak of blood from a torn vein or artery in the brain. This produces a collection of blood (haematoma), which may form in the brain or over its surface and compresses it.

Arrival at hospital: the emergency department

After the accident, the person with a brain injury should be taken to the nearest emergency department, where a doctor will carry out an initial assessment. After a serious accident it is possible that the person with brain injury may also have other injuries that need more urgent attention. Doctors will make an assessment and prioritise the treatment required based on the most urgent clinical need.

The medical team will check breathing and any blood loss, replacing any blood that has been lost with a transfusion. If the person is unconscious they will be unable to keep their throat clear and a tube will be put through their nose or mouth into the windpipe to help with breathing. This is called an endotracheal tube and is connected to a ventilator, which takes over the person's breathing mechanically. This ensures that the brain is kept well supplied with oxygen.

Medical staff may arrange various X-rays and will also check for further complications, such as blood clots or bleeding in the brain. To do this they will need to carry out a CT or MRI scan of the head. More information on brain scans is given in the following section on the neurosurgical unit.

This can be a very confusing time for relatives because many hospital specialists could be involved and urgent treatments are being carried out. You should be reassured that the injuries are being dealt with in the correct order of priority. You may have to wait for some time while urgent treatment is carried out and it will help everyone if you try to be as calm as possible.

You may wish to stay with your relative, but this is not always possible when speed of treatment is vital. On the other hand, you may find it upsetting to see your relative surrounded by tubes and machines and may prefer not to be there. There is no reason to feel guilty about this. Most emergency departments have a quiet room if you wish to be on your own.

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Neurosurgical unit

After the initial assessment, the doctors may decide to send the patient to a neurosurgical unit. This will help to obtain a much clearer picture of the brain injury, its potential effects and what treatment is needed. Neurosurgical centres are frequently based in major cities and so the person with a brain injury may need to be transported a long distance by ambulance or helicopter.

On arrival, the neurosurgeon will usually review the scans done at the local hospital or arrange for a brain scan if this was not done. This will help them to assess the extent of damage to the brain and decide whether an operation is necessary.

Brain scans

X-rays are only able to show whether the skull has been fractured. A CT or MRI scan, on the other hand, shows not only the bone but also the brain itself and can detect the presence of blood clots and oedema (swelling).

CT scan - 'Computerised tomography' (CT) uses a series of computerised X-ray pictures to show the structure of the brain in detail. This helps to show whether the brain is bruised or swollen and if there are any blood clots.

MRI scan - 'Magnetic resonance imaging' uses radio waves and a powerful magnet to create highly detailed images of the brain.

While brain scans can help the neurosurgeon to assess the extent of injury to the brain, it is important to understand that a scan cannot predict what kind of recovery will be made, nor how quickly.

Neurosurgery

If there is a blood clot large enough to damage the brain, or if there is pooling of blood or cerebral oedema, an operation will be needed. During surgery, a flap of bone is cut out of the skull over the site of the clot (a 'craniotomy flap'). Once the clot has been removed and damaged blood vessels repaired, the bone will then be replaced. In certain circumstances the bone may be left out and not replaced until later on in the recovery process. This decision will be made by the

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neurosurgeon during surgery.

The skull heals rapidly and normally leaves no area of weakness. Many people are particularly worried about the effects of an operation on the head, but in fact, the surgery itself is usually straightforward and without much risk. The most important factor is the injury that made the operation necessary in the first place.

An operation will also be needed if there is a wound that goes through the skull into the brain. Wounds of this sort may look frightening, but with proper treatment the external injury can often heal well. As with any traumatic brain injury there could be a future tendency to epileptic seizures, known as post-traumatic epilepsy, following this type of injury. The patient may be prescribed specific medication to reduce the risk of this occurring.

A neurosurgical operation is a delicate and lengthy procedure and can take a very long time. After the operation the person with a brain injury may take a long while to recover consciousness. This can be as a result of the anaesthetic, but is more often the result of the brain injury itself. The overall rate of recovery will depend on the severity of the brain injury, rather than on whether or not an operation has been performed.

Intensive care unit

After any neurosurgery has been carried out the patient may be taken to an intensive care unit (ICU) or neurological high dependency unit (HDU). Here they will be looked after 24 hours a day by highly trained staff, using specialised equipment to assess and treat them.

Just as in the early stages, staff will be checking the person's heart rate and blood pressure, testing brain function and controlling intake of fluids and food. Drugs may be used to keep your relative sedated at this time. The main priority is to reduce the risk of further damage while any bruising settles down and to prevent any further swelling of the brain.

The intracranial pressure may be carefully monitored using a special tube inserted into the head, usually called an intracranial pressure (ICP) monitor. This will not do any damage and will only leave a tiny scar under the hair. It will enable

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the doctors to know whether drugs are needed to relieve swelling and increased pressure.

Complications that may occur in the weeks following the accident and which could mean that your relative's condition worsens again, include:

- Subdural haematoma: A blood clot located in the space around the brain, which is not big enough to cause trouble at first, may grow with time and cause symptoms several weeks later. This is called a 'chronic subdural haematoma' and can usually be removed successfully by surgery.
- Hydrocephalus: The fluid in the spaces inside and around the brain known
 as cerebrospinal fluid (CSF) can build up, causing an increase in pressure
 on the brain. Again this can be treated quite simply by an operation. A shunt,
 which is a tube with a valve, can be placed in the brain to divert CSF away
 and relieve the pressure.

In the early stages a drip (or IV, for intravenous infusion) may be used to supply the person with essential nutrients. Once the person is past the emergency stage, but is still unconscious or unable to swallow, food may then be fed to them using either a nasogastric tube (which is placed through the nose and into the stomach) or a percutaneous endoscopic gastrostomy tube (more commonly called a 'PEG tube'). A PEG tube is inserted directly through the skin of the abdomen into the stomach. The food given is designed specifically for feeding in this way, and contains all of the essential nutrients needed to assist recovery.

If recovery is slow, a tracheostomy tube may be inserted directly through the skin of the neck into the windpipe. This replaces the endotracheal tube that was used in the earlier stages to help the person breathe, as this can begin to irritate the throat if used for longer periods. Once the tracheostomy is no longer needed the tube can be removed and the hole (stoma) will rapidly heal up without surgery.

Because unconscious patients are unable to control their bladder, a catheter may be inserted. This goes directly into the urethra (the outlet tube from the bladder) and drains the urine into an external bag.

It is not unusual for someone to have an epileptic seizure, or 'fit', soon after a severe head injury. The medical staff will be watching for this and will treat him/

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her if it occurs. Do not panic if this happens. It does not necessarily mean that the person will continue to have fits or develop epilepsy later on.

If there have been severe injuries to other parts of the body, it is quite common for other medical specialists to become involved. An orthopaedic surgeon might be asked to advise on broken limbs, a general surgeon to advise on abdominal injuries, or a cardiothoracic surgeon to advise on chest injuries. Sometimes maxillofacial surgeons can be involved, who are specialists in the repair of injuries to the face, bones and teeth. Plastic surgeons can be consulted if there have been problems with the skin or face, or perhaps burns to other parts of the body.

This can be a confusing time for families, as the person with a brain injury may be taken off for a series of tests, assessments or even operations. Be sure to ask the medical staff if you are unsure what is happening.

If you feel that your questions have not been fully answered, you can make an appointment to see the consultant in charge of your relative's care. This will give you more time to discuss any concerns. Before the appointment, write down any questions as you think of them, so that you don't forget to mention them to the consultant.

Coma

Whether it is for a few seconds or a few weeks, the usual immediate effect of brain injury is a loss of consciousness. Coma can be defined as a state of reduced consciousness in which a person shows no voluntary physical responses, or only reflex reactions.

There are different levels of coma, ranging from very deep, where the patient shows no response to pain, to more shallow levels, where the patient will respond to pain by movement or opening their eyes, or may make some response to speech.

Glasgow Coma Scale (GCS)

This is an aid which enables clinical staff to assess the potential severity of the

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brain injury. The minimum possible score on the scale is 3 and the maximum possible score is 15.

This assessment will be made by ambulance staff immediately following the injury. A maximum score of 15 indicates that the person can speak coherently, obey commands to move, and can spontaneously open their eyes.

Glasgow Coma Score Severity of brain injury

14 - 15 Mild

9 - 13 Moderate

3-8 Severe

Coma stimulation programmes

It is quite common for family members to feel 'useless' at this time and to be desperate to do something to help their relative. A coma stimulation programme (sometimes called a coma arousal programme) is an approach based on stimulating the unconscious person's senses of hearing, touch, smell, taste and vision individually in order to help their recovery. There is still controversy over how effective it is to try to stimulate a person in coma. However, most would say that such programmes have some beneficial effect.

A stimulation programme must only be started after discussing this with the clinical staff, who will advise you what might be appropriate at that particular stage in the recovery process.

Examples of activities that could form part of a coma stimulation programme are available in our publication <u>Coma stimulation: suggested activities.</u>

It is important that friends and relatives do not feel that they have to spend all day at the person's bedside. The patient will need quiet periods as well and it is important not to 'over-do' the stimulation - short periods are enough. Relatives themselves will also need to take a break and try and get some sleep from time to time.

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Recovery from coma

Unfortunately nobody can tell you how long the coma will last, or what effects the brain injury will have in the long term. No two brain injuries are the same and people recover at different rates.

If the person recovers consciousness quickly (i.e. in days, rather than weeks or months), this is obviously a good sign. However, it is important to emphasise that no accurate predictions can be made in the early stages. There have been many people who have been through many weeks or even months of unconsciousness who have gone on to make good recoveries. There are also people who recovered consciousness quite quickly, but have then experienced major problems at a later stage. Nevertheless, the length of coma is one of the most accurate predictors of the severity of long-term symptoms. The longer the coma, the greater the likelihood of lasting problems.

Recovery from coma may start with the eyes opening, then gradually responding to pain (touch) and then to speech. People do not just wake up from a coma and say, "Where am I?" as is sometimes represented in films. It is a much more gradual process as the brain begins to try and co-ordinate all of the information it is receiving.

Vegetative state (VS)

A small number of people sustain a brain injury so severe that they remain unconscious for a long time and are classed as being in a vegetative state. They will usually be able to breathe for themselves and there will be some spontaneous eye opening, but they will only respond in a reflex way. There will be no evidence of awareness and no ability to communicate. When this has persisted for more than one month after the injury, the person may be described as being in a continuing vegetative state (PVS).

Minimally conscious state (MCS)

This is a state in which the person is no longer in a coma or a vegetative state, as they may show some degree of interaction with the environment. However, these responses are too inconsistent to be able to show that they are fully aware of and

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and understand what is going on around them.

For more guidance on VS and MCS, refer to the Royal College of Physicans' Prolonged Disorders of Consciousness guidelines at www.rcplondon.ac.uk/guidelines.

Post-traumatic amnesia

After the period of unconsciousness, the injured person may appear to be awake and aware of what is happening, but may begin to behave in a bizarre or uncharacteristic manner and may be unable to remember day-to-day events properly. This is a period known as post-traumatic amnesia (PTA). Typical signs of the person being in PTA are as follows:

Loss of short-term memory:

- The patient may be able to talk to relatives, friends and nurses, but may not be able to remember these conversations a short time later
- They may not know the time, or the day of the week, or where they are
- The person may recognise family and friends but be unable to process the fact that they are in hospital or have had an injury of some kind.

Restless, agitated or bizarre behaviour:

- The person may appear very confused, agitated, distressed, anxious, or frightened
- They may show uncharacteristic or disinhibited behaviour, such as swearing, shouting or hitting out at people and even sexual behaviour, such as taking their clothes off or openly masturbating
- They may become unusually quiet, docile, over-friendly to everybody, clinging or childlike
- They may also have a tendency to wander off, or to try to get out of bed even
 if they have broken limbs or other injuries. They may talk and behave as if
 they are being held prisoner and have to escape, or as if they have to go to
 work or to a meeting, or are going on holiday. The risk of falls or further injury

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by pulling out catheters or intravenous drips can be a problem at this time

 In some cases the person may not recognise anyone, but may ask for relatives or friends whom they haven't seen for years, or believe that they are still a child or a much younger person themselves.

Length of PTA

As with the length of coma, the length of PTA is important as this can be an indicator of the severity of brain injury and the likely long-term effects. PTA may last a few minutes, hours, days, weeks, or even months. A brain injury is usually classed as severe if the person has post-traumatic amnesia for 24 hours or more.

PTA is assessed by the clinical staff by asking the patient a number of questions at daily intervals. The first group of questions is concerned with awareness of time, place and personal identity, for example, 'What is your name?' or 'What day of the week is it?' A second group of questions relates to the patient's awareness of the accident, for example, 'What was your last memory before the accident?' A patient deep in PTA will not be able to answer these questions correctly. The end-point of PTA is difficult to define, although as the patient emerges from PTA their answers become more accurate and more sensible.

What can be done about PTA?

A person who is in PTA is not in control and cannot be held responsible for what they do or say during this period. This can be a very difficult and distressing time for relatives, but it is important to remember that this is a normal stage of recovery and is one that will pass. The following suggestions may help:

- Try to stay as calm as possible. Seeing others distressed, but not understanding the reasons why, will make the person feel more confused and agitated.
- Try to ignore disinhibited behaviours, even though these may be upsetting.
 Again, seeing other people distressed may only increase the patient's agitation or distress.

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- The presence of familiar friends and relatives at this stage can be very helpful. The person recovering from unconsciousness can easily be confused by unfamiliar faces and a strange environment can add to this confusion.
- Reduce the risk of harm. This may mean having someone to sit with the
 patient at all times, particularly if they are likely to wander off or try to get out
 of bed. During the day, a rota of familiar faces may be useful, with perhaps
 an assigned nurse at night. Discuss the situation with the clinical staff.
- If the person asks the same questions over and over again, or insists on something which is simply not true, do not try to force them to remember, or correct them repeatedly. This will simply increase the level of agitation.
 Gradually, the person will come to hold onto more information and will begin to make more sense of the world around them.
- Be sure to take time out for a break or to share the visiting/ sitting with others. It is very important to look after yourself and being tired makes everything harder to cope with.

It may be of some comfort to the family to learn that the person with a brain injury is likely to have little memory of this time, or that it may only be experienced as a 'bad dream'.

General hospital ward

Once they are out of the emergency stage, there is less need for intensive nursing and your relative may be moved onto a general hospital ward.

They may still be highly dependent on nursing care. They may not be able to swallow properly yet and may still require the nasogastric tube that was used for feeding while in intensive care. Your relative may not have recovered enough strength to hold their hand up, or to sit up on their own and may not be able to communicate properly yet. However, they will know, even if in a rather confused way, that their family and friends are with them and this will be a comfort and a great source of strength to them.

You may feel at this stage that you want to do more for your relative and you can

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discuss this with the nurse in charge. You may be shown how to take over simple nursing tasks or rehabilitation exercises, although it is important that this is done under the supervision of the hospital staff, since if things are done wrongly they can cause further complications.

Early rehabilitation

It is natural at this stage for relatives and friends to be anxious about the prospects for future recovery. The effects of brain injury differ widely from person to person, depending on how severe the injury was and what parts of the brain were damaged. Any one patient's condition will be made up of a mixture of these effects, in varying degrees of severity. People with less severe injuries may spend a short time in coma and may go quickly through the stages of rehabilitation and be back at work in a month or two. Those more severely affected are likely to still need care and treatment a number of years after the accident. Fortunately, the brain seems to have a remarkable capacity for re-learning many skills that have been lost and even people with severe injuries can often make a reasonable recovery.

Physical abilities

In the very early stages, even when the patient is still unconscious, physiotherapists will be involved in the care of the person with a brain injury. This is to prevent unnecessary complications arising, such as developing a chest infection, skin breakdown (pressure sores), or contractures of the limbs as a result of muscle spasm.

Once the person regains consciousness, it is important to get them to sit up in bed or in a chair as soon as possible. Later, by using a 'tilt table' that can be tilted until upright, the patient can become gradually used to standing and taking their weight on their feet. As they become used to doing this, they may then start to take steps - at first with the help of staff, then a mobile frame and then, as their balance improves, with less and less support. Some people may not be able to walk independently and will need to use a wheelchair.

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Movement in arms and legs

The areas of the brain that control movement of the arms and legs are often affected by brain injury. Even when the person is still unconscious you may be able to see that one arm or leg is not moving like the other one, or is lying in an unnatural position. The muscles may not be working at all, which makes the limb loose and floppy. Alternatively, the muscles may contract unnaturally, causing stiffness or 'spasticity'. If a joint is being pulled out of place by muscles that are over-contracting, a splint may be needed to control the movement. This may be worn all the time or just at night.

Until movement returns it is important to make sure that the joints are not allowed to stiffen, either from lying still or by being pulled into an abnormal position by the muscles. The physiotherapist will begin by trying to relax the tight muscles and will try to move the joints through their full range of motion. This must be done carefully, since too much stretching can damage the joints and ligaments. Once some movement returns, exercises will then be carried out to develop and strengthen the movement and to correct any problems.

Posture, balance and knowing where the body is in space

When the patient first starts to sit up in bed, they may be unable to hold their head and their body may fall to one side if not supported by pillows. This is because they need to regain strength in their trunk muscles and re-learn how to use these muscles to control posture. The balance organs in the inner ear can also be damaged by brain injury, causing balance problems and dizziness.

Another difficulty for the patient is knowing where their body is in relation to the things around them. After a severe brain injury, the mechanisms that regulate this process tend to be faulty. As a result, the patient may have no idea of what their position is, whether they are sitting safely or are about to fall off the edge of the chair, or whether an outstretched hand will meet the bed, the wall or an empty space.

Exercises will be needed to help the patient begin to recognise where their arms and legs are in relation to their own body and the space around them.

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Memory and concentration

One of the immediate things you may notice when your relative first regains consciousness is that they can only concentrate on what you are saying for a very short time. They may soon forget what you tell them and may ask the same questions over and over again. They may also become tired very quickly, which makes their concentration and memory even worse.

While the person's memory for the past before the accident may be quite good, their memory for what has just happened is often the last thing to recover. Dealing with any new situation is likely to confuse the person and they may have great difficulty in learning from recent experience.

The first things the person may recover might be their memory for familiar and automatic activities, like repeating the days of the week and counting. It may be helpful to try to get the person to talk about other things they may remember, such as family history, friends or their job.

For more information, refer to the Headway publication <u>Memory problems after</u> brain injury.

Fatigue

Managing fatigue is often one of the most important areas in helping people after brain injury. If the person becomes tired during rehabilitation exercises and their progress slows down, this is a signal that they need to rest straight away. It is not helpful to push them to do more, as they will only become exhausted and will need to rest more than ever.

For more information, refer to the Headway publication *Fatigue after brain injury*.

Discharge from hospital

Many people are left with a variety of psychological and physical problems after brain injury and these can often be helped considerably by an intensive period of inpatient rehabilitation. It is possible at this stage that the person may be

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transferred to a specialist brain injury rehabilitation unit. For further information on this, see Headway's publication *Rehabilitation after brain injury* or contact the Headway helpline.

If the patient is judged to be able to return home straight from hospital, it is vital that the following areas are assessed first by a member of the hospital team:

- What remaining difficulties does the patient have physical, cognitive, emotional and behavioural?
- Will the patient be safe in his/ her home environment? Can a home visit be arranged to check this?
- How will his/ her continuing needs for rehabilitation be met?
- What type of support and follow-up will there be at home?
- What medications will he/ she need? When should they be taken, and for how long?
- Could there be any risk to others (e.g. children in the family) if the patient returns straight home?
- Have the patient and family been advised on how best to manage the patient's remaining problems and those that are likely to occur later?

A formal discharge meeting to address the above issues should be held before the patient is sent home. Social services staff should attend the meeting, together with hospital or rehabilitation staff, close family members and possibly the GP.

It may be possible for the person with a brain injury to be allowed home on one or more day or overnight visits, on a trial run basis, before being sent home. This will help family members to find out whether any adaptations are needed for the home (e.g. a wheelchair ramp) and will give them the opportunity to ask questions and get help while still in contact with the hospital team.

On leaving hospital, the patient and family should be given contact details of the neurological rehabilitation team, so that they have someone to contact for advice in the future.

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Conclusion

If you are reading this publication shortly after your relative or friend's injury, the likelihood is that the long-term effects will be unclear at this stage. We cannot provide answers to all the questions you will have, but hopefully the information here has been helpful.

As time goes on and your relative's recovery progresses you may find different challenges presenting themselves. If they have now been discharged, then you may have a clearer idea of the problems to be faced. Services for people in this situation vary widely throughout the UK, and in many cases are not available. It is therefore especially important to access as much information as possible so you know how to get the right support.

Headway is here to help in any way we possibly can, visit our website for further information or contact our helpline on 0808 800 2244 (Monday - Friday, 9am-5pm) or helpline@headway.org.uk.

As a charity, we rely on donations from people like you to continue being able to provide free information to those affected by brain injury. To donate, or find out how else you can get involved with supporting our work, visit www.headway.org.uk/get-involved.

If you would like to leave feedback for this publication, please consider completing our short survey at www.surveymonkey.co.uk/r/hwpublications or contact us at publications@headway.org.uk.

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