Headway - the brain injury association
June 2025

the brain injury association

The effects of brain injury

and how to help

This publication has been written for the families and carers of people who have had a brain injury. It covers some of the main difficulties that arise after brain injury, together with some suggestions as to how to deal with them.

For more guidance on how Headway supports people affected by brain injury, visit our website at www.headway.org.uk.

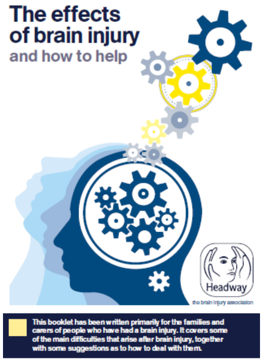
Contents

Helpline: 0808 800 2244
Email: helpline@headway.org.uk
Web: www.headway.org.uk

This publication is also available as a printed booklet. For more information or to order, contact 0115 924 0800 or visit shop.headway.org.uk/publications-9-c.asp,

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



The effects of brain injury
and how to help

Headway
the brain injury association

This booklet has been written primarily for the families and carers of people who have had a brain injury. It covers some of the main difficulties that arise after brain injury, together with some suggestions as to how to deal with them.

Introduction

This publication is an introduction to some of the main difficulties that can affect individuals and their families after brain injury, together with some suggestions as to how to deal with them. Although the publication is intended mainly for families, friends and carers, brain injury survivors themselves may also find the information useful.

The main effects of brain injury are grouped into three categories, which are dealt with in turn:

- **Physical** - affecting how the body works
- **Cognitive** - affecting how the person thinks, learns and remembers
- **Emotional and behavioural** - affecting how the person feels and acts

The bullet points that appear throughout the text highlight practical ways in which you may be able to help someone with a brain injury. While these tips are intended to be helpful, it is important to ensure that you do not 'take over' entirely and allow the person to become too dependent on others. It is best to try to maintain a balance of helping and stepping back, so that the brain injury survivor is able to maintain or rebuild their independence, their self-esteem and sense of identity.

Headway provides further publications that deal specifically with many of the issues raised in this one. Details of relevant publications are provided throughout.

What is brain injury?

An acquired brain injury (ABI) is an injury caused to the brain since birth. There are many possible causes, including a blow to the head, tumour, stroke, lack of oxygen to the brain or infections, such as encephalitis.

This publication deals in particular with one type of brain injury: traumatic brain injury (TBI), typically caused by a blow to the head. There are many possible causes such as road traffic collisions, falls and assaults. However, much of the information is also applicable to other kinds of brain injury.

How are people affected by brain injury?

After a mild head injury, brain function can be temporarily impaired and this is often referred to as concussion. This can lead to difficulties such as headaches, dizziness, fatigue, depression, irritability and memory problems. While most people are symptom-free within a few weeks, some can experience problems for months.

For more information specific to mild injuries, see our publication *Mild head injury and concussion*.

This publication mainly deals with the effects of more severe brain injuries.

The more severe the brain injury, the more pronounced the long-term effects are likely to be. Survivors of more severe brain injury are likely to have complex long-term problems affecting their personality, their relationships and their ability to lead an independent life.

Even with good rehabilitation, support and help in the community, survivors and their families are likely to face uncertain and challenging futures. If you are currently trying to cope with these difficulties, the information in this publication can help.

Physical effects

Physical effects of brain injury affect how the person's body works. As the brain controls everything that our body does, there are many possible physical effects of brain injury. This section discusses some of the more common physical effects of brain injury and how you can support the survivor with coping with these issues.

Mobility can be affected following brain injury. Movement can become slow and balance can be affected. Some people may need a wheelchair or other mobility aids, because their poor balance and co-ordination means they cannot walk without support, or are at risk of falling. The fact that they use a wheelchair does not necessarily mean that the person cannot stand or walk for short distances.

- If the person is able to stand or walk, ask how exactly you can help them - e.g. where they would like you to stand, how long they need you to hold or support them for, etc.

- Offer a wheelchair-user the opportunity to move to another seat, or to move about more freely within the room.

- Check with a doctor or physiotherapist which physical activities the person is able to take part in.

For more information on these issues, see our publication *Balance problems and dizziness after brain injury*.

Spasticity can be present. Limbs may be stiff or weak, and the range of movement limited. Often one side of the body is affected more than the other, depending on the area of the brain that is injured. Spasticity may cause pain or discomfort. If this occurs it is advisable to seek help from a GP, who may be able to prescribe drugs to reduce muscle spasms.

- Ask the person what they are able to do and how you can help.

- It may help if you stand on one side of them to provide support when transferring from a wheelchair to another chair, or when getting in or out of a car. They may also ask you to sit at one side of them at the table, so that you can help out during mealtimes or with other activities.

Weakness (hemiparesis) or paralysis (hemiplegia) often affects one side of the body more than the other, depending on the side of the brain that is injured (each half of the brain controls the opposite side of the body). It is particularly common after stroke. This could mean that help is needed during personal care and when getting dressed or undressed. It may also affect continence, so continence aids may also be needed.

- Understanding the person's difficulties will help you to be more patient if they are slow to carry out activities.

- A variety of specialist aids may be purchased to make things like getting dressed a little easier.

For more information on these issues, see our publications *Weakness or paralysis (one-sided) after brain injury* and *Continence problems after brain injury*.

Ataxia is irregular, uncontrolled movement or tremor affecting the co-ordination of movements. The person's hands may be shaky or clumsy, and handwriting may be difficult or impossible. It may be difficult for the person to complete work, hobbies or activities of daily living such as washing and dressing.

- Ensure items such as kettles, pans and cups are safe for the person to use.

Uncontrolled movements could cause difficulty in safe handling of such items. Many safe, non-spill models are available from disability equipment providers.

- Encourage care in movement, but try not to make the person anxious about what they are trying to do.

- It may be more comfortable for the person to type on a computer rather than trying to communicate by writing.

- Assistance with filling in forms may be needed.

For more information on this issue, see our publication *Ataxia after brain injury.*

Sensory impairment. Sensation of touch on the skin may be reduced, lost or exaggerated. It may also be difficult for the person to know where their limbs are positioned without looking at them. Eyesight may be affected, and this may not be correctable with glasses. Odd postures or walking patterns may also be explained by sensory impairments. Taste or sense of smell may be impaired or lost, either in the short or long term.

- A magnifying glass may improve the person's ability to read small print.

- An eye test should be carried out to check whether the person requires glasses.

- It may help to use lined paper for handwriting tasks and to use double spacing between lines.

For more information on these issues, see our publication *Visual problems after brain injury* and *Taste and smell issues after brain injury*.

Fatigue. Excessive tiredness is common to all severities of brain injury, including mild injuries. Tasks that we take for granted, such as getting dressed or walking around can require much more effort after brain injury. It is important to allow for rest periods at regular intervals during the day, and not to feel that everything has to be done at once.

- Take the lead from the person you are helping. Encourage them, but try not to expect more from them than they are able to give.
- Learn to recognise signs of the person's fatigue, and encourage them to rest when these begin.
- Always try to plan ahead and prepare enough time to do an activity. Space activities apart and alternate more difficult tasks with easier ones.

For more information on this issue, see our publication *Fatigue after brain injury*.

Difficulties with speech. Slow, indistinct or rapid speech is common after a brain injury. It may be hard to understand the person's speech at first, but the listener may learn to 'tune in'.

Some people may lose the ability to speak altogether. Remember, their difficulties with speech do not mean they have lost their ability to express themselves or their thoughts in other ways.

- Encourage the person to speak slowly and clearly. Give them plenty of time to respond.
- If you cannot understand their speech or gestures, ask for the statement to be repeated, or phrased in a different way.

- Ask simple questions, as appropriate, such as *'Where is…?', 'Point to…', 'Show me…', 'Do you mean…?'*

- Repeat any words that you have understood, to save the person from needing to repeat them all over again.

- Try to avoid making assumptions about what *you* think has been said. Never guess the meaning of what has been said just to get you out of a tight spot or to cover your embarrassment.

- Do not ignore the person if you do not understand what they are trying to say. Ask someone else to help you to try to understand what is being said.

For more information on this issue, see our publication *Communication problems after brain injury*.

Epilepsy. Brain injury can make some people prone to epileptic seizures or 'fits'. Many people who have had a seizure after a brain injury are given a drug for a number of years to reduce the chance of it recurring. The drug may have an overall 'dampening' effect on the person's level of arousal, and therefore on the performance of everyday tasks. Remember the added effect that this could have if the person already has excessive fatigue.

- If someone has an epileptic fit, protect the person from injury by moving people and objects (such as furniture) out of the way.

- Never put anything in the person's mouth and do not try to restrain them.

- Loss of bladder control may occur during a seizure and it is important to try to maintain a person's dignity. Ask onlookers to move away to provide privacy and try to cover the person up to spare them embarrassment.

- When the fit is over, turn the person into the recovery position, with something soft under their head, until they are ready to sit up.

- It is usual for the person to want to sleep afterwards, so try to make this possible for them.

For more information on this issue, see our publication *Epilepsy after brain injury.*

It is important to remember that a person who suffers from seizures may not be allowed to drive, and should contact their licensing agency for advice. For more information in this see our publication *Driving after brain injury.*

Hormonal imbalances. Brain injury may cause damage to the hypothalamus and/or pituitary gland, which are small structures at the base of the brain responsible for regulating the body's hormones. This can lead to either insufficient or increased release of one or more hormones and conditions such as hypopituitarism or neurogenic diabetes insipidus.

Symptoms can include depression, impotence, mood swings, fatigue, muscle weakness, reduced body hair, fluctuating body weight, sensitivity to cold, increased thirst, excessive production of dilute urine, and many others.

- If you suspect hormonal problems, you should encourage the person to speak to their GP. If appropriate, they should be able to refer to an endocrinologist, who can run a series of hormone level tests.

For more information on this issue, see our publication *Hormonal imbalances after brain injury*.

Sexual functioning

There are a number of different parts of the brain that are responsible for the skills involved in sexual activity. When these are injured, it can cause problems with sexual functioning and wellbeing. This can have an impact on existing and future relationships, and affect how the person feels about themselves.

Sexual functioning is a very personal and sensitive subject. Whether you can offer support or advice will depend on the relationship you have with the person.

For more information on this issue, see our publication *Sex and sexuality after brain injury*.

Cognitive effects

Cognitive effects of brain injury affect how the person thinks, learns and remembers. As the brain is responsible for our thoughts and mental processes, there are many possible cognitive effects of brain injury. This section discusses some of the more common cognitive effects of brain injury and how you can support the survivor with coping with these issues.

Problems with memory, particularly short-term and ‘working’ memory, are common after brain injury. Some people may be unable to remember faces or names, what they have read or what has been said to them. New learning may be affected, or memories from before the injury may be disrupted.

- Ask the person to write down essential information on a noticeboard or notepad. Regularly remind them to look at what has been written.

- Present new information in very small amounts, so as not to overload the person. Try presenting the information in several different ways (e.g. visually as well as verbally).

- Journals and diaries can help with recording what has already been done in

- the day and what needs to be done in the future.

- Have a designated place for important items in the home, and keep a list of where things are kept.

For more information on this issue, see our publication *Memory problems after brain injury.*

Language loss (aphasia). This may be 'receptive' (difficulty making sense of what is said or read) or 'expressive' (difficulty finding the right words to say or write), or both. This can be very frustrating for the person and for others, and patience is needed on both sides. Remember, just because a person cannot express themselves, does not mean they do not need or want to be heard.

- Use simple sentences when speaking to the person, and present only one idea at a time.

- Be patient, and help out tactfully.

For more information on this issue, see our publication *Communication problems after brain injury*.

Impairments in visual-perceptual skills. The person may have difficulty making sense out of pictures and shapes, finding their way around a building, or drawing or constructing objects. Some people have difficulties recognising certain objects (agnosia), such as human faces (prosopagnosia or 'face blindness').

Although vision and hand control may be good, the person may appear to be 'seeing' only part of the scene. Sometimes people can only attend to one half (usually the right side) of objects, even though they can still see the other side if prompted. This condition is known as visual neglect and can cause people to only eat the food on one side of the plate, only shave one side of the face or even dress only one side of the body.

Impairments in visual perception may mean that a person cannot assess the speed of oncoming traffic accurately. It is particularly important therefore to make sure that they are safe when crossing roads.

- For visual neglect seek a referral to an ophthalmologist or orthoptist.
- When reading it can be helpful to use a visual cue, such as a ruler, to get the person to scan the whole page with their working field of vision.
- Encourage the person to use safe crossing points on busy roads.

For more information on this issue, see our publication *Visual problems after brain injury.*

Reduced initiative and problems with motivation

Problems with getting started on tasks are common, and can often be mistaken for laziness. These problems may also be a symptom of depression (see section *Emotional and behavioural effects* for more information).

- Remember, the person isn't being lazy and being impatient with them won't help.
- Help to structure the person's day and avoid long periods of inactivity.
- Prompt the person with tasks that they are struggling to initiate, and if necessary provide help to get them going.

- Give all the encouragement you can, but try not to insist on the person doing something that they really do not want to do, or would not have done prior to their brain injury.

Reduced concentration span. This is very common, and can also be affected by memory problems. Completing tasks can be an issue, and the task may be abandoned before reaching the end. The person may initially appear eager to start a task, but then lose interest very quickly.

- Reduce the number of distractions in the environment.

- Keep tasks short and within the person's concentration span.

- Give appropriate encouragement, such as verbal or physical prompts, to help the person to keep to the activity being carried out.

Reduced information processing ability. It may be difficult for the person to organise facts in their mind, particularly if there are also memory problems. 'Information overload' can be quickly reached, and can cause frustration and anger.

- Try not to give the person too much information at once.

- Help the person to break down tasks and identify the steps involved in solving problems.

Repetition or 'perseveration'. The person may be unable to move onto another topic in the same conversation, or they may return to the same topic over and over again. They may also repeat the same action, appearing unable to break the cycle.

- Tell the person that you are going to change the topic or activity, so that you can both concentrate on something new.

- Give a reminder if necessary that you have changed direction and are now focusing on something new.

Impaired reasoning may affect a person's ability to think logically, to understand rules, or to follow discussions. The person may easily become argumentative due to lack of understanding.

- Try to resist entering into or trying to win arguments. It will only make both of you upset and agitated.
- Explain information in different ways, and don't expect to much from the person.

Impaired insight and empathy can cause difficulties in accurately perceiving and interpreting one's own and other people's behaviour and feelings. Putting oneself 'in someone else's shoes' can be almost impossible. The person may also have an unrealistic view of themselves and others, and may not understand that they have certain problems. This may lead to unattainable goals being set, which then leads to failure and frustration.

- If the person's behaviour seems particularly self-centred, remind them of other people's feelings and give feedback, but remember that you may not be able to change their behaviour.
- Provide frequent, clear and simple explanations of why a problem is being treated, or why the person is unable to do something.
- Be cautious about telling someone that they will 'never' be able to do something. Instead, encourage small goals to be set that can be reached quickly, so that progress is visible.

- Do not encourage a person to try to complete a task or activity that they will be unable to achieve, as this may lead to anxiety, frustration and low self-esteem.

For more information on this issue, see our publication *Insight and awareness after brain injury*.

Many of the effects of brain injury described in this section are collectively known as executive dysfunction. For more information on this, see our publication *Executive dysfunction after brain injury*.

Emotional and behavioural effects

Emotional and behavioural effects of brain injury affect how the person feels and behaves.

Emotions and behaviour are closely linked, as our feelings often determine how we behave. As the brain is responsible for these processes, there are many possible emotional and behavioural effects of brain injury.

This section discusses some of the more common emotional and behavioural effects of brain injury, and how you can support the survivor with coping with these issues.

Personality changes. For many families, the worst consequence of brain injury is feeling as if the person who was once known and loved has somehow slipped away, together with their character and their individual ways. For the person with a brain injury, losing a sense of their own identity can be traumatic and frightening.

For this reason, experiencing brain injury can be similar to going through bereavement : the healing process is made up of grief, denial, anger, acceptance, and finally, resolution. However, this process can take many years to run its course, and the feelings experienced may not present in any particular order.

Sometimes the impact of brain injury means that the person remains unaware of what has happened to them and how they have been affected. If they are free from physical effects, other people may also fail to recognise the 'hidden disability', such as the cognitive or personality changes that have taken place. This can leave both brain injury survivors and their families feeling very isolated.

It can be particularly difficult if the person with brain injury has children. While children are often surprisingly able to come to terms with changes in their lives, they may not be able to fully understand what has happened to their mum or dad and why they are different from before. More information on this is available in our publication *Supporting children when a parent has had a brain injury*.

- Take time to grieve for what has been lost. Acknowledge it, but allow yourselves to move on to a future full of new possibilities.

- Share memories and tangible reminders - photos, stories, objects and mementos that bring back happy times.

- Rediscover your strengths, both as individuals and as a family: the good times you have enjoyed and the life you have shared can help you find meaning in the new life you are going to build.

For more information on this issue, see our publication *Identity after brain injury.*

Mood swings or '**emotional lability**'. The person may have a tendency to laugh or cry very easily, and to move from one emotional state to another quite suddenly.

- Be on hand to reassure or calm the person when necessary, especially in social situations.

- Model calm behaviour yourself. Disregard laughter when a situation is not funny by ignoring it rather than joining in.

- Suggest another activity, by way of distraction, until the person calms down.

Depression and sense of loss are common. Depression may be caused by damage to the brain's emotional control regions, but can also be associated with the person gaining an insight into the effects of their own injury.

After a serious accident or illness, many things that are precious to the individual may be lost forever. There may be much sadness, anger, guilt and confusion surrounding this. There may be lost skills such as cooking, writing or sport; lost independence (getting dressed, going shopping, driving); lost lifestyle (friends move on and no longer include the injured person in their plans); lost career (most severe brain injury survivors are unable to go back to work); lost companionship (many brain injured people say that they feel very lonely).

- Understanding the person's feelings will give you the insight to deal sympathetically with any difficult behaviour.

- Be a good listener and acknowledge what is said to you.

- Acknowledge that it is perfectly reasonable for them to be depressed, due to the trauma they have been through.

- Try to get the person involved in structured activities, including daily exercise, as much as possible.

For more information on this issue, see our publication *Depression after brain injury*.

Anxiety can be another consequence of brain injury. Life has been changed forever, and the future can look frightening. Anxiety can quickly lead to frustration and anger, and needs to be identified and alleviated as early as possible.

- Try to be positive yet realistic in your attitudes about the future.
- Build confidence by setting simple and achievable tasks, before making them progressively more difficult.

For more information on this issue, see our publication *Anxiety after brain injury.*

Frustration and anger. Frustration can build up quickly, especially when things that were once so easy are now difficult or impossible. The resulting anger may be very difficult for the person to control.

- Encourage the person to express their anger safely. It is alright for them to shout out or thump a cushion if it helps them to relieve tension. After this, it is helpful to do something more calming, such as standing still, dropping their shoulders, and breathing slowly.
- Try to get the person to agree to redirect their emotional energy by doing a different activity or task. A change of environment can also help.
- If anger has been targeted at others, discuss the outburst after everyone has had a chance to calm down. Try to find reasons why the person became so upset. Suggest better ways of dealing with the situation next time, including avoiding or anticipating ‘triggers’ that can cause them to become angry, and let the person know that you are willing to help them with this.

For more information on this issue, see our publication *Anger after brain injury.*

Disinhibition. There may be a loss of control over social behaviour, so that the person may behave in an over-familiar manner or may make sexual advances with the wrong people at the wrong time. This behaviour can be embarrassing and upsetting for loved ones.

- Encourage behaviours that are more socially acceptable. This may include providing ‘coaching’ prior to social events. Regularly remind them of what is expected of their behaviour in public, as they may quickly forget.
- Explain briefly and firmly that you object to their behaviour, then make no further reaction. If you over-react you may reinforce the behaviour.
- Remember that learning and memory may be a problem, so you may have to repeat yourself several times.

Impulsiveness. A person with a brain injury may tend to speak or act without thinking things through properly first.

- Encourage responsibility for what is said or done by drawing attention to the consequences of their impulsive behaviour.
- Try to ensure that the person does not get into situations where their impulsive behaviour could put them in serious danger.

Obsessive behaviour can occur. For example, a person may be afraid that their possessions will be stolen, and may check their belongings repeatedly.

- Remember that reasoning and behaving in a rational manner may be difficult for the person with the brain injury.

- Reassure the person as best you can, and help them to move on when they become ‘stuck’ on an issue.

A useful general rule is to be generous with approval when the person with a brain injury behaves appropriately. Feedback and positive reinforcement will make improvements in behaviour more likely to occur.

Do not expect the person to deal with a situation outside of their abilities, as this is setting them up to fail.

By adopting an attitude of acceptance, being patient and using your mannerisms to create an atmosphere of relaxation, potentially volatile situations can be more easily diffused and ‘flashpoints’ avoided.

Coping in the longer term

Because traumatic brain injury generally starts with one event, that is often how we think of it - a single event, taking place in a specific moment of time. In fact, the injury itself is only the beginning of a process - a journey, on which the person with the brain injury, and their family and friends, travel together.

This can be a long journey. The aftermath of brain injury is measured in months and years, rather than by days and weeks. Wherever you are on your own brain injury journey, it is important for everyone to take one day at a time. Sensible planning for the future is important, but if goals are fixed too far in the future, you or the brain injury survivor may miss the small important triumphs which are the real markers of progress.

It may help to keep a diary of progress, and encourage family members and friends to contribute with their own observations and stories. You may also like to add photographs and descriptions of the occasions they represent. When you look back after a few months, it will surprise you to see just how much progress has been made. A diary can also provide a ‘reality check’ for the person with brain injury, especially if they lack insight into their situation, or feel depressed because they can’t recognise improvements.

Families and carers need supporting too. Sometimes the needs of the brain injury survivor can seem so great that those close to them feel guilty if they express needs of their own. They may be in need of a break from the situation, or may even feel that they have run out of energy. There will inevitably be times when things seem to go wrong, or when the strain of coping and caring can seem too much to bear. A long journey is often tiring, and carers need to be able to allow themselves time to rest and to take themselves away from their immediate situation.

There are many sources of help and information available, be it in the form of friends and relatives or healthcare professionals. Do not be afraid to ask for help.

Further information for carers is available in our publication *Caring for someone with a brain injury.*

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

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

The print edition of this publication received a Highly Commended Award at the British Medical Association Patient Information Awards 2012.

Updated June 2025. Next review June 2027.