A guide to living with brain injury

New beginnings: Supporting you or someone you know to manage life after brain injury

Brainkind

Disclaimer

This guide provides general information about living with brain injury to help support your discussions with healthcare professionals.

We have made sure the content is as accurate as possible and include best practice around brain injuries.

If you have any questions or concerns about the information in this guide, please get professional or specialist advice.

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“Knowledge is power. Whether you have a brain injury yourself, or you are a family member of someone who has one, or a health or care professional, I hope that the information in this guide helps you to feel empowered.” Emma Rich, who had a brain injury in 2021

About Brainkind

"I want to start back getting on these two pins of mine. Eventually, I will. I feel strong. I have a lot of positivity inside me."

Tony Jenkins who has had neurorehabilitation at Ty Aberdafen, our centre in Llanelli, Wales

We improve the lives of people with brain injuries across the UK. Our two hospitals and 15 rehabilitation centres support people with brain injuries to regain the skills they have lost through neurorehabilitation.

This type of treatment helps us understand the effects of a brain injury on a person's cognitive, emotional, physical and social skills. Our clinical teams use a range of therapies to respond to ongoing assessments of these skills, including physiotherapy, psychological therapy and occupational therapy.

We also have 32 services in the community. Our dedicated teams of specialists work closely with each person with a brain injury to understand what they want and why, and shape support.

From rehabilitation to long-term care, our brain injury services help people to move forward with their lives.

You can find out more about us at brainkind.org.

Contents

Welcome, from Emma

Emma Rich, 46, had to relearn how to walk, talk and write after her brain injury. Here, she welcomes you to this guide and explains how it might help.

There is hope after a brain injury and time is a great healer. The brain is so flexible. It's just fascinating how much it can renew itself.

That's what I most want to say as I introduce you to this guide to living with a brain injury.

I fell down the stairs at home after blacking out in November 2021. I was taken to Brighton Hospital with a big bleed on the brain and my husband John was told that I would not recover with any meaningful quality of life. Thanks to my medical team, rehabilitation and my family's support, I have come a long way.

I'm pleased to have helped produce this guide which has lots of information about how a brain injury can affect you, physically and emotionally. I think that understanding this helps to manage your anxiety around having a brain injury. You can be the master of your own healing.

Getting advice is really important. So, this guide has lots of guidance that can help with everything from managing your finances and relationships to going back to work. It includes the voices of people living with a brain injury so you can hear directly how others have coped.

Knowledge is power

I know that it can be confusing, unsettling and stressful when you, or someone in your family, first has a brain injury. You need as much information as possible.

Knowledge is power. Whether you have a brain injury yourself, or you are a family member of someone who has one, or a health or care professional, I hope that the information in this guide helps you to feel empowered.

If you are anything like me, you will get tired of talking about having a head injury. You will want your independence back. And you can get it. There is the chance to be able to do things you used to do. Maybe in a different way, but you can still do things and have fun.

Emma Rich

Section One:

What is an acquired brain injury?

This section of the guide explains the causes of brain injuries and looks at how common they are.

Living with a brain injury can be tough. But you are not alone. There are others who are going through similar challenges.

So, what is an acquired brain injury?

It is when someone's brain is damaged after birth. The causes of an acquired brain injury include:

- **A bang to the head, which is called a traumatic brain injury.**
- **Strokes, including a brain haemorrhage or bleed in the brain.**
- **Brain tumours.**
- **Encephalitis, or inflammation of the brain, from an infection or when your body can not tell the difference between your own cells and foreign cells. This causes the body to mistakenly attack normal cells (known as an autoimmune response).**
- **Hypoxia, when the brain is damaged because it does not get enough oxygen.**
- **Exposure to alcohol, drugs or other toxic substances.**

Some types of brain injury, like brain tumours and certain types of stroke, affect a specific part of the brain. Other types of injury, such as a traumatic brain injury and hypoxia, usually cause widespread damage to the brain. This means that some people may experience very specific difficulties, whereas others might have problems with several things.

Different areas of the brain specialise in different functions, and control different parts of the body. This is shown by the diagram below called "Penfield's Homunculus". It shows how the body is represented on the somatosensory cortex of the brain, the area responsible for receiving and processing sensory information, such as touch, temperature and pain. The size of the body part represents the size of the area of the brain devoted to it. The most sensitive areas are larger in size, which is why the hands are bigger than the legs and feet in the diagram.

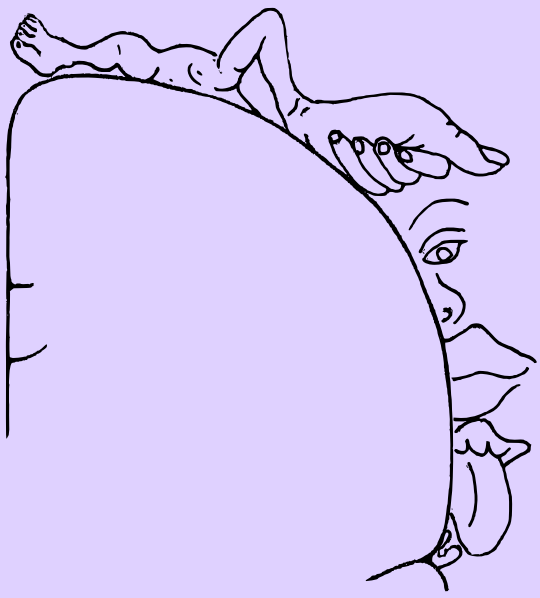


Figure 1: The Penfield Homunculus

How common is acquired brain injury?

The terms “incidence” and “prevalence” refer to how common a particular condition is. In the case of brain injury, “incidence” relates to the number of people who sustain a brain injury in a particular period, usually one-year. “Prevalence” refers to the total number of people who have ever sustained a brain injury.

Incidence and prevalence of brain injury are typically estimated using the number of people admitted to hospital. To get an idea of the total number of people who sustain a brain injury in a particular year, or the total number of brain injury survivors, we have to add the figures across all the causes of brain injury.

For example, traumatic brain injury and strokes. Doing this excludes people who might not have received hospital treatment.

Because some people with brain injuries do not get immediate medical treatment, it can be challenging to gain an accurate picture of how common brain injury is. Sometimes, brain injury is masked by other health problems, such as heart attacks.

The charity Headway reported that, in 2019-2020, 356,699 people in the UK were admitted to hospital with an acquired brain injury. But statistics suggest that over 1.3 million people are living with the long-term effects of an acquired brain injury.

Further reading

- *Head Injury (The Facts)*. Audrey Daisley, Rachel Tams and Udo Kischka. (2009). Oxford University Press.
- *Head Injury: A Practical Guide (Speechmark Editions)*. Trevor Powell. (2004). Routledge.
- *Life After Brain Injury: Survivors’ Stories*. Barbara Wilson, Jill Winegardner and Fiona Ashworth. (2013). Routledge.
- *The Never-Ending Journey: Living with Brain Injury*. Antoinette Anthony-Pillai. (2013). Instant Apostle.

> “After my brain injury, I must have read everything there is to read about that and stroke and recovering from a stroke.” Terry, 49, had a brain injury in 2021.

Section Two:

How a brain injury affects someone?

This section of the guide explains the effects caused by short and long-term brain injuries.

We use our brain to do just about everything. So, if it gets injured, it can affect us in lots of different ways.

> “I had been unconscious for about 15 minutes. Mood changes are common with concussion, and mine started the moment I woke up.”

“Yes, I was confused; I was also, maybe more accurately, bemused. All I needed to do was lie in bed and let people examine me. It was a lot like floating on an inner tube down a river: I remained still and the scenery changed. I mostly felt cheerful and upbeat, even though I didn’t really understand what was going on.”

Elizabeth Lopatto, a science journalist, writing about her brain injury in the Guardian

Early stages of a brain injury

When someone has a brain injury, they will experience a change in consciousness. This might be obvious, such as when they are completely unconscious, or in a coma, or it might not be so noticeable. For example, someone who has concussion from a sports injury may feel very dazed and confused.

The less someone is able to respond, the deeper their level of unconsciousness. How long someone is unconscious for is also used as an indicator of how serious their brain injury is. It can vary from a few seconds to many months. The longer someone is unconscious for, the more severe their brain injury is likely to be. But while the person is unconscious, the body can start to naturally heal.

As the person who has had a brain injury emerges out of unconsciousness, they may seem to be aware of what is going on. But they may not be able to retain new memories or say where they are, or what the date is. When this is happening, the person can seem confused and may say strange things. For example, sometimes people might think they are 10 or 20 years younger than they really are.

Feeling confused, not knowing where you are, and not fully understanding the situation, can be very alarming. People are likely to get tired easily and might feel disheartened and become irritable if they try to do too much too soon. When someone with a brain injury goes through this stage, family and friends have a really important role to play to reassure them.

“My prognosis was really bad. I had a Glasgow Coma score of three. My whole brain was full of blood. They told my husband I had died.”

“I was in a coma for a week. When I woke up, I felt really, really annoyed with myself for being away from my boys who are 15 and 12.

I remember being in the hospital and one of the therapists was constantly putting tests in front of me and saying things like: ‘You realise you are not going to go back to work, and you are not going to be as intelligent as you were.’ I wanted to scream at him that I just needed sleep. When you are recovering from a brain injury, initially, sleeping is one of the biggest healers.”

Emma Rich,
who introduces this guide.

Did you know?

Someone’s level of consciousness is usually measured by the **Glasgow Coma Scale** (also known as GCS), which scores your level of responsiveness.

It starts from three which is no response at all and goes up to 15, which is being able to walk, talk and be fully aware of your circumstances.

Later stages of a brain injury

As someone emerges from the period of unconsciousness, or altered awareness, longer-term effects of their brain injury become more obvious.

> **“When I had my stroke, I was worried about regaining mobility and getting some sense of normality.”**
>
> Terry, 49,
> had a brain injury in 2021.

These include:

- **Physical effects – problems with movement and senses like, vision, touch or taste.**
- **Cognitive problems – including thinking processes, such as memory and concentration.**
- **Emotional changes – feeling anxious or irritated, or changes in behaviour, like someone’s self-control or motivation.**

How a brain injury affects someone physically

The brain controls the majority of what we can do physically. It helps us coordinate movements in our body. The right-hand side of the brain is responsible for movement in the left-hand side of the body and vice-versa. If one side of someone’s brain is more severely injured, movement in one side of their body might be more affected than the other.

The physical effects of a brain injury depend on where the damage has happened and how serious it is. It can be difficult to know how someone might be physically affected and how they could recover. But there are some physical effects of brain injury that are more common than others.

Mobility problems

These are common after a brain injury and can include issues with balance and slow movement. For some people, the loss of control over movement can be severe and they may need to use a wheelchair. Others might lack control in one limb or walk with an unusual gait. They might need a cane to help them. These aids can be temporary or more long-term. It might be difficult for the person with a brain injury, and those around them, to adapt to the new need for these aids.

> **“I used to use my wheelchair to move around the building. But now I can walk around on my own.”**
>
> Paul, who had a road traffic accident in 2014 and moved to Ty Aberdafen in Llanelli, Wales.

Muscle tightness

“Spasticity”, or muscle tightness, happens when signals from the brain to the rest of the body are disrupted. This leads to uncontrolled tightening of the muscles. It can happen suddenly and might be alarming. Muscle tightness can be triggered by certain activities and is often worse at night. It can affect someone’s movement and cause muscle stiffness, weakness, pain and discomfort.

Spasticity can vary from “mild”, which means someone might move quite slowly, to “severe” which makes any kind of movement seem impossible. The length of time that a person deals with this issue can vary. It can come and go and may not always need treatment. A physiotherapist, your rehabilitation team or GP will be able to advise you on this.

“I had four strokes which have affected my brain.”

“I can think about what I want to say but sometimes I find it hard to get it out.I speak in single words and short sentences. I have limited use of the right side of my body, particularly my leg, arm and hand, and have needed care for over 30 years.”

Keith, 67, is supported by Myland House, our community service for people with acquired brain injuries in Colchester.

Muscle weakness

Muscle weakness or paralysis can affect one side of the body more than the other. When this happens, it is known as “hemiplegia”. This is especially common after a stroke and the side of the body that is affected will be opposite to the side of the brain that has been injured.

Other types of paralysis are “paraplegia”, which affects the lower body, and “quadriplegia”, from the neck down.

People with muscle weakness will need help from those around them. This can include physical support to carry out day-to-day activities, such as getting dressed, moving about and travelling, and rehabilitation to improve their fitness.

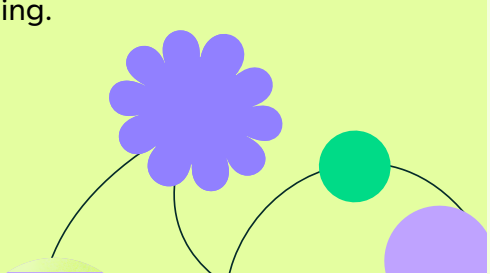
When someone does not have control over the muscles in their face, mouth or throat, they may find it difficult to talk or swallow, or both. For example, when someone talks, their speech can sound mumbled because the muscles are not moving enough.

Or their voice may be low in volume because it’s difficult to control the amount of air coming from their lungs (known as “poor breath support”). For more about communicating with a brain injury, see section three in this guide, called Supporting someone with a brain injury to communicate.

The same muscles are used for swallowing, so people may also have difficulty eating and drinking. This could be when food is in their mouth or throat. For example, they might lose food from their lips, or it could go down their airway. Food going into the airway can be fatal as the person may choke. Speech and language therapists can prescribe different food consistencies to prevent this. They can also help with therapies to improve muscle tone.

Problems with coordination

A brain injury may lead to ataxia, which is when someone cannot control their muscles. They might have problems with movements that require coordination, such as walking or picking up objects. A brain injury survivor with ataxia may have an unsteady gait or trouble with fine motor skills, such as writing or buttoning their shirt. Some people have an "intention tremor". This means their hand or arm shakes when they try to reach for something.



> "Something I've found difficult since my brain injury is that I can't tie my shoelaces. Which is quite frustrating because it's such a basic thing, you've done it all your life since you were a little child."

Terry, 49,
who had a brain injury in 2021.

Changes to the senses

Sensory issues involve loss of, or changes to, the senses. These may improve with time or be more long-term. These changes can occur on one, or both, sides of the body, depending on the brain injury.

These include:

- **A reduced or lost sense of touch, called "hypoesthesia".**
- **Feeling overwhelmed by sounds or tactile sensations of pressure, or increased sensitivity to different textures, that were not an issue before.**
- **Losing sensitivity to heat, putting people at risk of burning themselves or getting too cold.**
- **Blurred, double, or worsened peripheral vision. Or loss of vision in one or both eyes.**
- **A loss of, or changed, taste or sense of smell.**
- **A changed sense of "proprioception". Known as the 'sixth sense', proprioception allows us to know where the different parts of our bodies are at any given time. When this sense is affected, it may be difficult for someone to know where their limbs are positioned.**

Pain

Pain is common after any injury, and brain injury is no different. It is part of the healing process, and usually goes away after some time. Unfortunately, some people experience chronic pain, which is pain that lasts longer than 12 weeks. Pain after a brain injury can include headaches and neurological pain. This is nerve pain caused by the brain sending random signals to the body, or as a side-effect of muscle tightness.

Pain can have a negative impact on someone's health and wellbeing. They might, for example have trouble sleeping, or experience fatigue and low mood.

There are different ways to deal with pain after a brain injury. Medication, exercises and therapy can help. Treatment will depend on the type of pain and whether it is chronic (long term) or acute (short term). People who are experiencing pain after a brain injury can talk to their GP or a rehabilitation practitioner to discuss what is best for them.

Fatigue

Fatigue is persistent tiredness and can happen after a brain injury for various reasons. It can be part of someone's physical problems, and be connected to poor sleep, anxiety and post-traumatic stress. Fatigue can make it extremely difficult to carry out some tasks, reduce someone's motivation and affect their mood.

Improving sleep habits can help reduce fatigue. You can find tips to improve sleep in the Managing sleep problems section of this guide. Taking breaks during the day can also help. But, if neither of these seem to work, a GP or rehabilitation professional will be able to make a referral to a specialist or give further advice.

Epilepsy

Someone with a brain injury is more likely to have seizures and epilepsy. There are different types of seizures, and you are only diagnosed with epilepsy after having two or more of them:

- **Early seizures are more likely to happen in the first week after someone has had a brain injury.**
- **Late seizures are ones that happen more than a week after a brain injury. They can occur years after a brain injury and are more likely to recur and result in epilepsy.**

Seizures can be distressing, both for the person experiencing them and those around them. They can cause further damage to the brain and be life-threatening.

It is important to speak to a healthcare professional, like a GP or rehabilitation specialist, if someone experiences a seizure after a brain injury. These professionals can help with getting a diagnosis and managing the seizures. For example, they can prescribe medication and help identify potential triggers.

Coping with the physical effects of a brain injury

Every brain injury is unique and affects each person in a different way. So, there is no established pattern for recovering from brain injury.

People who were in hospital as a result of brain injury are likely to be referred to specialist rehabilitation services, such as those run by Brainkind. This can include assessment and support from a physiotherapist, who will be able to help with physical problems.

A GP or other healthcare professional may refer someone with a brain injury to outpatient or community-based specialists for further assessment or treatment. This can include physical treatments, medication or other therapies.

Sometimes, people with a brain injury might not experience any physical problems. Keeping fit and active can help someone to cope with both the physical and psychological effects of a brain injury as this:

- **Releases natural painkilling hormones called serotonin and endorphins.**
- **Can help develop a healthy routine.**
- **Provides many health benefits, including improving sleep, mood and anxiety.**
- **Helps manage fatigue.**

Did you know?

When you have had a brain injury, you can have scars on your head where hair does not grow back. Simple head massage techniques, with a natural massage balm (like ones made from germanium oil), will help to manage the wound. This can simulate hair growth and help with the scar tissue, making it less itchy.

Cognitive problems

"Cognition" refers to thinking, remembering, speaking, calculating, and concentrating. The brain underpins all thinking processes so any of these can be affected by a brain injury. The most common cognitive problems which someone might experience when they have a brain injury are:

- **Memory impairment:** Usually, someone will have clear memories of events in the past but may not be able to remember things that have happened since their brain injury.
- **"Executive Difficulties":** This term describes the functions of the brain responsible for planning, integrating, and organising the activities of other parts of the organ. The word "executive" is used because these functions are similar to what a chief executive in a company does – planning and organising the activities of the whole company.
- **Difficulty concentrating**
- **Difficulty processing information**
- **Difficulty speaking, called aphasia:** This happens when the communication centres of the brain are damaged. Some people cannot speak at all. Others cannot find the right words. Some people may also have difficulty with written language, such as reading, writing or using numbers.

> "I have struggled with aphasia since my brain injury, finding the right words"

"I had to re-teach myself to write and speak. Now, it only happens that I can't find the right words when I'm tired."

Emma Rich, who introduces this guide.

> "I am more mindful of how I do things now so that I can be sure I am doing things correctly."

"I do misunderstand information and have difficulty completing forms and letters, so I have to seek guidance. I find this frustrating as I used to be an accountant, which involved forms and figures."

Bill, 51, hit his head when having an epileptic seizure and came to Brainkind's West Heath House for rehabilitation in June 2020.

Emotions

People often experience changes in their emotions after they have had a brain injury. They may feel:

- **Irritable:** This can be seen as an emotional change (feeling irritable), or as a behaviour change (behaving in an irritable manner).
- **Up and down:** Someone's emotions might fluctuate much more suddenly than is usual. For example, they might lurch from sadness to happiness – or vice versa – in a moment, or swing from laughing to crying, or from being calm to angry very quickly.
- **Inconsistent:** Someone with a brain injury may not experience emotions or feelings in the way they did before. They know how they would normally feel in particular circumstances, but do not respond in the same way.
- **Anxious or depressed:** They might feel less confident because of their brain injury.

"After my accident, expressing and caring for myself was hard."

"My mood and emotions were affected, making it difficult for me to socialise. With the help I have received, my weight, sleep and mood has improved so I feel healthier. I am feeling good and enjoy socialising with other people."

Paul, who had a road traffic accident in 2014 and moved to Ty Aberdafen.

Behaviour

Initially, changes in someone's behaviour after a brain injury might be because they are confused. Later, difficulties with regulating behaviour can become more apparent. This can include someone becoming more:

- Impulsive than they used to be, and not thinking before they act.
- Irritable and aggressive.
- Placid, people might become quieter than they used to be.
- "disinhibited" they no longer control impulses they previously would have inhibited. For example, people may say things which are rude or undiplomatic, or they may make sexual remarks, or display sexually disinhibited behaviour.

These problems may resolve as someone recovers from a brain injury. But if the brain injury is severe, they can continue. So, the person who has had a brain injury will need to relearn how to control and overcome these changes.

Motivation

It is very common for someone to lack, or appear to lack, motivation after a brain injury. This can be because of a number of reasons.

A brain injury can make it difficult for a person to think of things to do. Or they may not be able to decide between alternatives. Even if they can do both of these, the person may have an "initiation deficit", which means they cannot "press the button" that triggers them to do an activity. A person with this problem may tell you exactly what they plan to do but sit around all day never getting started. Others can get started on doing something but lose their way or go off at a tangent. They have difficulty formulating a satisfactory plan to follow. Or, they have a plan but do not keep to it as they get distracted. Or they do not monitor their behaviour.

It is natural for those around the person to interpret this as a deliberate lack of drive, or laziness. Yet, this is far from the truth. With appropriate prompting and support, someone with a brain injury who is experiencing these problems can become very energetic and able to participate in activities.

Section Three:

How alcohol can cause brain damage

This section of the guide aims to help people to understand how alcohol and other substances can affect the brain.

It explains:

- **How alcohol use can cause damage to the brain**
- **Different types of alcohol-related brain damage**
- **Rehabilitation for this type of brain injury**

For information about how alcohol can affect someone's recovery after a brain injury, the effects it has on thinking, memory and problem-solving skills, and advice on how to manage alcohol intake, have a look at **Section five: Supporting people's health and wellbeing after a brain injury.**

The facts about alcohol-related brain damage

Some brain injuries can be caused by alcohol. For example, someone could fall when drinking and hit their head. Drinking a lot of alcohol over a long time can also lead to brain damage, which is called alcohol-related brain damage (ARBD). This type of brain injury is not as well-known or understood as other types of brain injury, leading to misconceptions.

Here, we dispel some of the common misconceptions about ARBD.

Alcohol and dementia

Dementia is a general term for loss of memory, language, problem-solving, and other thinking skills that is severe enough to interfere with someone's day-to-day life. There are over 200 illnesses which can lead to dementia – the most common one is Alzheimer's Disease.

ARBD has historically been referred to as "alcohol-related dementia" as the symptoms resemble those of other dementias. However, ARBD is not a "true" dementia. This is because, the decline is not progressive if the person stops drinking. In fact, many people experience a significant improvement in cognition after they have stopped drinking for a while. So, ARBD is a type of acquired brain injury.

ARBD and Wernicke-Korsakoff's syndrome

A further area of confusion is the use of the term "Korsakoff's" to refer to all types of ARDB. The name comes from a Russian psychiatrist who first reported that using alcohol over a long time causes dementia-like symptoms.

Around the same time, a German neurologist called Wernicke, discovered a degenerative disorder of the brain – acute encephalopathy. This is caused by drinking alcohol for a prolonged period. He said this affected cognition, including thinking, memory, and problem solving.

These two doctors were describing the same syndrome but with different degrees of severity. Consequently, the illness became known as Wernicke-Korsakoff's Syndrome.

Wernicke-Korsakoff's syndrome and vitamin B

Wernicke-Korsakoff's syndrome develops because of a deficiency in vitamin B1, also known as thiamine. The term refers to two different stages of the disease.

Wernicke's encephalopathy is the "acute" phase and Korsakoff's syndrome is the "chronic" phase. Long-term use of alcohol reduces the body's ability to absorb vitamin B from a regular diet. People who drink a lot often also have a poor diet. With continued abstinence, the damage done by Wernicke-Korsakoff's syndrome does not get worse. But it may not get better, particularly if it is in the chronic stage. If these symptoms are identified in the early stages, encephalopathy can be treated with high doses of vitamin B. This often leads to a good outcome. The most important thing is that the person receives treatment before too much damage happens. Recent evidence suggests that continued treatment for several months has promising results.

Alcohol-related neurotoxicity

Alcohol can have a direct effect on the brain. It is thought to attack a substance called myelin that helps the nerve cells in the body to send messages to the brain. This can affect people's cognition, such as memory and thinking. There is evidence that this damage is reversible when someone stops drinking and that people's cognition recovers.

Effects of alcohol

Drinking alcohol can create a sense of euphoria, a feeling of intense excitement and happiness. It also has a sedating effect on the brain, which affects cognition and coordination as someone's blood-alcohol levels rise. The feeling of euphoria is short-lived and wears off quite quickly. The sedative effect on cognition and co-ordination steadily increases the more alcohol is consumed.

How often have we heard tales of people waking up the morning after a night of heavy drinking with little or no recollection of the previous night's events? Alcohol can affect the area of the brain responsible for judgement and making decisions, which can make people lose their inhibitions and act differently from how they normally would.

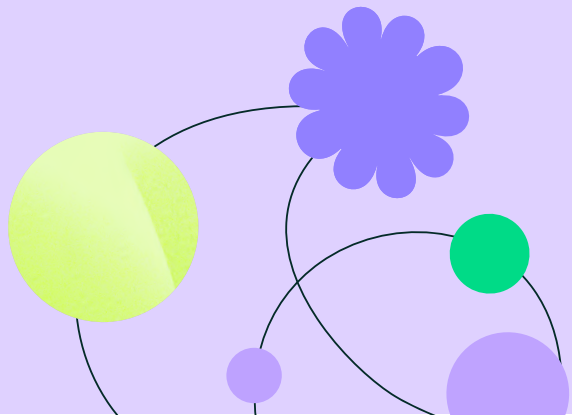
Effects of alcohol-related brain injury

The effects of alcohol-related brain damage are like those of dementia. There are usually severe memory problems, such as being unable to recall recent information. This is because the area of the brain responsible for creating new memories is affected. Recalling information from before the brain injury can also be difficult. There may also be difficulties with planning, problem-solving and reasoning.

Confabulation, a severe form of false or distorted memories, is often seen in people with alcohol-related brain damage. This typically happens when both memory and cognition are affected, which is common for people with alcohol-related brain damage.

Rehabilitating someone with an alcohol-related brain injury

There is not a lot of research available on rehabilitation following alcohol-related brain damage. But there is some evidence to show that rehabilitation techniques used to treat and support people with traumatic brain injury and strokes can be just as effective. Any behaviour issues caused by alcohol, not the brain injury, may also need to be addressed to help someone recover as much as possible.



Further reading

Books and articles

- *Head Injury (The Facts).* Audrey Daisley, Rachel Tams and Udo Kischka. (2009). Oxford University Press.
- *Head Injury: A Practical Guide* (Speechmark Editions). Trevor Powell. (2004). Routledge.
- *Life After Brain Injury: Survivors' Stories.* Barbara Wilson, Jill Winegardner and Fiona Ashworth. (2013). Routledge.
- *The Never-Ending Journey: Living with Brain Injury.* Antoinette Anthony-Pillai. (2013). Instant Apostle.

Websites

- *Living with Traumatic Brain Injury by the Model Systems Knowledge Translation Centre:* **msktc.org/tbi**
- *Physical Effects of Brain Injury by Headway:* **www.headway.org.uk about-brain-injury/individuals/ effects-of-brain-injury/physical-effects /#mobility**
- *Physical Effects of Stroke, by the Stroke Association:* **www.stroke.org.uk/effects -of-stroke/physical-effects-of-stroke**
- *Sitting exercises by NHS:* **www.nhs.uk/live-well/exercise strength-and-flexibility-exercises/ sitting-exercises**
- *Stroke recovery exercises by My Stroke Guide* **mystrokeguide.com asol?gclid=EAIaIQobCMIneqOwqOM-AIViJBoCR18_wX8EAAYAiAAEgJiFPD_BwE**
- *The Brainy Speech Therapists Podcast* by Jan McIntosh-Brown and Helen Maclean: **open.spotify.com/show/7FY6 mecaz1YSqpr2twyFPl** or wherever you download your podcasts.

> **"Before my accident, I was drinking a lot so staff at West Heath House supported me to get counselling to manage my alcohol intake."**

"I am more mindful of how I do things now so that I can be sure I am doing things correctly."

Bill, 51, a former accountant from Walsall, who hit his head when having an epileptic seizure.

The Headway Brain Injury Identity Card

The charity Headway provide identity cards for people with brain injuries. These can be used to explain the effects of their brain injury to others and request any support someone may need.

For example, so that doctors, sales assistants and bus drivers allow more time when they are interacting with the person.

Find out more about applying for the card at www.headway.org.uk /supporting-you/brain-injury-identity-card/

Section Four:

How someone's brain injury affects others

This section looks at how a brain injury can affect other people and offers advice on how to manage difficulties in relationships.

A brain injury changes lives. Not only of the person who has had the injury but also their partner, children, friends and colleagues, who will need to support them.

How might someone with a brain injury appear to others?

When someone has a brain injury, their family, friends and colleagues might feel like they are very different to how they used to be. But the person with the brain injury might not think they are different at all.

Why? Because people with a brain injury are often unaware, or only a little bit aware, of the difficulties they experience. They may think they have not changed at all. This is called “lack of self-awareness” or “lack of insight”. It is more commonly experienced when someone’s injury is very severe. People with milder injuries are often extremely aware of their difficulties.

> “A lot of people's families feel distress when someone has a brain injury.”

“When you are really tired, and in pain, tensions in the family can increase because it's hard not to lose your temper. Family members are getting used to things as well. Getting used to someone being ill, and that they’re going to have to look after them. There are so many things to get your head round.”

Emma Rich,
who introduces this guide.

Lack of self-awareness

Someone with a severe lack of self-awareness cannot acknowledge that they have any difficulties. They may even be unaware that they have had a brain injury. They might recognise the more tangible, observable difficulties, like problems with their mobility or physical things they cannot do. But it can be more difficult for them to see problems with their behaviour, memory or social skills.

If someone has milder impaired self-awareness, they can understand their difficulties, and recognise when they are having problems. But they cannot anticipate situations when they are likely to have them. For example, someone may realise they cannot concentrate for as long as they used to and notice when their ability to focus starts to fade. But they cannot anticipate that this is likely to happen during a meeting, or when they watch a film. So, the person might not do anything to prevent or overcome these difficulties, for example, making sure they have a break.

The impact of someone's lack of self-awareness

Problems of self-awareness can often lead to difficulties between the person with a brain injury and their family. This is because the person with the brain injury often cannot understand why they are being prevented from returning to their normal day-to-day life.

Or that they need help and support to do everyday things.

These differences of viewpoint can be difficult for all concerned and can lead to friction in relationships. It can help for everyone involved to develop an understanding of how the brain works and the impact an injury can have on motivation, initiation and self-awareness. This can help someone to develop a more tolerant attitude to the person with a brain injury and ways of supporting can become clear.

> "I recently had a cerebral haemorrhage. It doesn't always make you the nicest person in the world for a while"

"I've seen the videos of me in hospital! As my brain recovered and then improved, the TEM folks (staff and people supported at Thomas Edward Mitton House) were perfect in offering tolerance of that. Also, they offered a home, food and the high-quality talks we all shared. I learned a lot there about how the brain actually works."

George,
who had a traumatic brain injury after a fall in 2019, and was at Thomas Edward Mitton House for rehabilitation.

How a brain injury can affect family life

Dealing with an acquired brain injury can be one of the most difficult things a family ever faces. There are many changes to cope with, including:

- **Families can experience great uncertainty in the initial recovery period, which can be traumatic for everyone.**
- **Depending on how severe the brain injury is, once someone has recovered physically in hospital, they will return home. The person may need long-term care, so families will have to think about who provides this.**
- **Some people need rehabilitation when they leave hospital before they can go home.**
- **Sometimes, people might only be referred to rehabilitation several years after their injury, when its impact on daily life changes. Someone with a brain injury may need to stay elsewhere to have rehabilitation, which means family members could be separated temporarily or long-term.**

Families often provide long-term support and direct assistance to someone with a brain injury. This experience can be unsettling and isolating. In this section, we look at how brain injury can affect family life.

> “Our family member’s injuries have been a constant reminder of what can happen within a split second.”

“In the last 16 months, our lives have changed to a point never imagined and always on our minds.”

Relative of someone staying at Fen House.

“I lived in a supported living bungalow for three months. It meant that John and my children could come to visit at the weekends.”

“I had the chance to get strong by myself. My family was involved too. The psychologist did some sessions with my husband and the boys, explaining about the long-term impact of a brain injury, which was really good because it was a big shock for them.”

“Access to families in rehabilitation is critical. It helps to maintain relationships and provide stability and normality for the person with a brain injury, plus much-needed support and education for families.”

Emma Rich,
who introduces this guide.

How might someone's changes in personality and behaviour be seen by others?

Everyone recovers from an acquired brain injury in their own way. The effects of it vary from person to person.

Parents, partners, siblings, children and friends can notice big changes to someone's personality and behaviour. This can be upsetting and difficult to understand. Many people worry that behaviour and personality changes may be permanent. Health professionals cannot predict this either, which can add to people's anxiety and distress.

Problems with regulating emotions can lead to anger, aggression or inexplicable changes in someone's behaviour. It can often be more difficult for friends and family to cope with these than with physical or cognitive difficulties, like memory or attention problems.

Some of the most distressing personality and behaviour changes are:

- **Aggression**
- **Sudden changes in mood**
- **Self-centeredness**
- **Impulsivity**
- **Sexual and social disinhibition**
- **Lack of empathy, the ability to understand and share the feelings of others.**

These changes can be particularly distressing to family and friends when the person with a brain injury is not aware of them.

> "It's sort of affecting my wife because I think she didn't want to move in with me at the minute. It's understandable because I think she's worried about me getting another stroke."

Ian, 46,
who had a brain injury in 2021.

> “Graham Anderson House set me firmly on the right track to maximise my recovery.”

“Their personalised and intensive rehabilitation programme improved my cognitive ability and gave me strategies to manage my condition. They helped me and my family to understand the injury and its effects.”

Robert Collins,
who had a brain injury in 2018.

How a brain injury can affect relationships with a partner

When someone has a brain injury, their relationship with their partner can break down over time. But this is not inevitable. Having access to support can promote better relationships between spouses. This can include information on how a brain injury affects relationships, couples therapy, and practical help, like having support from a family member or friend who can share some of the care.

Sometimes, partners, as well as other relatives and friends, may find it difficult to know when it is safe for the person who has a brain injury to take on roles they used to do, like managing finances, looking after the children, or cooking. It can be helpful to discuss these roles and responsibilities with rehabilitation professionals. They will be able to advise you about any risks, and what strategies can be put in place to reduce them.

See the section called ‘Enjoying sex after a brain injury’ to find out more about the impact of brain injury on intimate relationships.

How a brain injury can affect relationships with children

When a parent has a brain injury, it can change the nature of the relationship they have with their child or children, as well as the other parent. It could change the child's everyday routine, for example. So, they may be taken to football practice, or another activity, by a different parent. Or, if the parent is in hospital or having rehabilitation elsewhere, the child may miss their parent being at home in the evening to spend time with them.

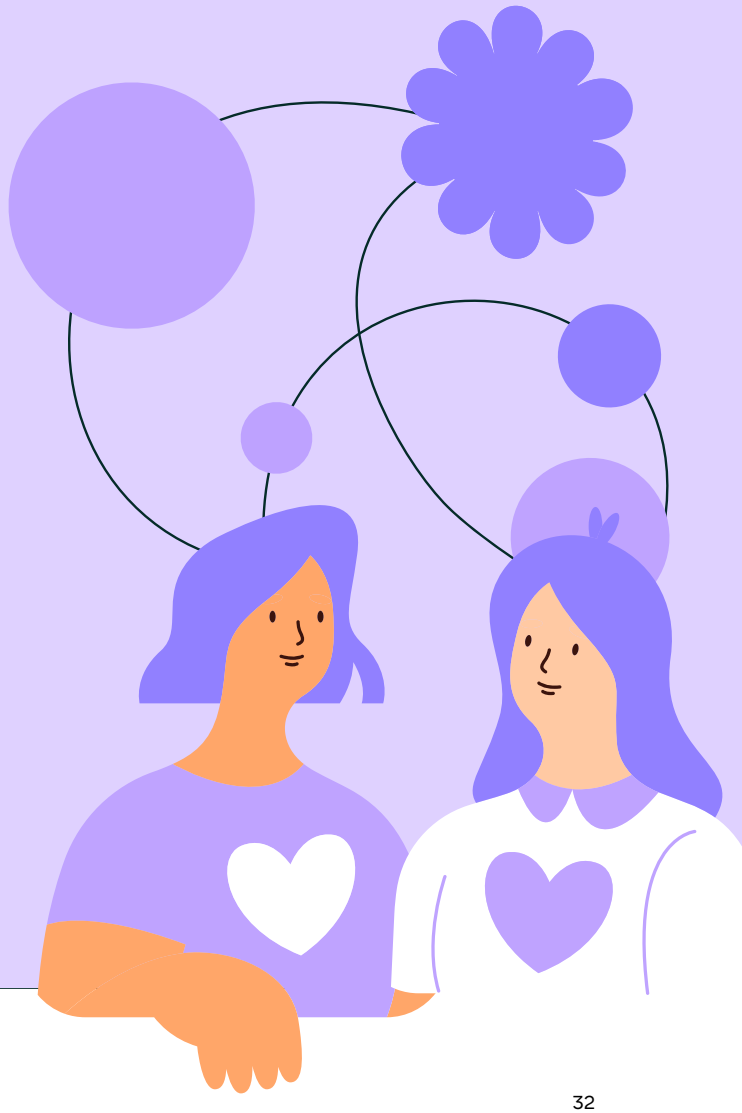
Children will need time to process their emotions about the changes in family life. Talking about brain injury, or using stories or drawings to explore their feelings, can help to do this.

Older children and teenagers can benefit from being involved in their parent's recovery. They could go along to rehabilitation meetings and speak with staff or take part in support groups with other young relatives. This can help children understand how a brain injury can affect their parent, and what they can do to support them.

At Brainkind's rehabilitation centres, we create opportunities to include children in someone's recovery. For example, using Zoom or Skype calls, and having private family areas with toys and other entertainment. We encourage and support families to resume their usual routines, like going for coffee or to church, watching a football match or creating a cosy film night.

> "It affects my relationships and things with my family. It's slowed them right down. You have to be careful what you say."

Jane, 55,
who had a brain injury in 2022.



Why family support is important

Most people with brain injuries who need inpatient rehabilitation at a centre will return to live with their families. Family members will have lots of practical questions about how this changes their lives, including ones relating to financial, housing and employment issues.

Family support is a hugely important part of someone's rehabilitation. It can be really helpful to try to focus on what has been achieved since someone's brain injury. For example, the person may now be able to walk a few steps unaided, having previously used a wheelchair.

Staying emotionally close as a family and committed to the rehabilitation process is vital. It can be helpful for family members to try to accept imperfections in themselves and others and to adjust their life goals if they need to.

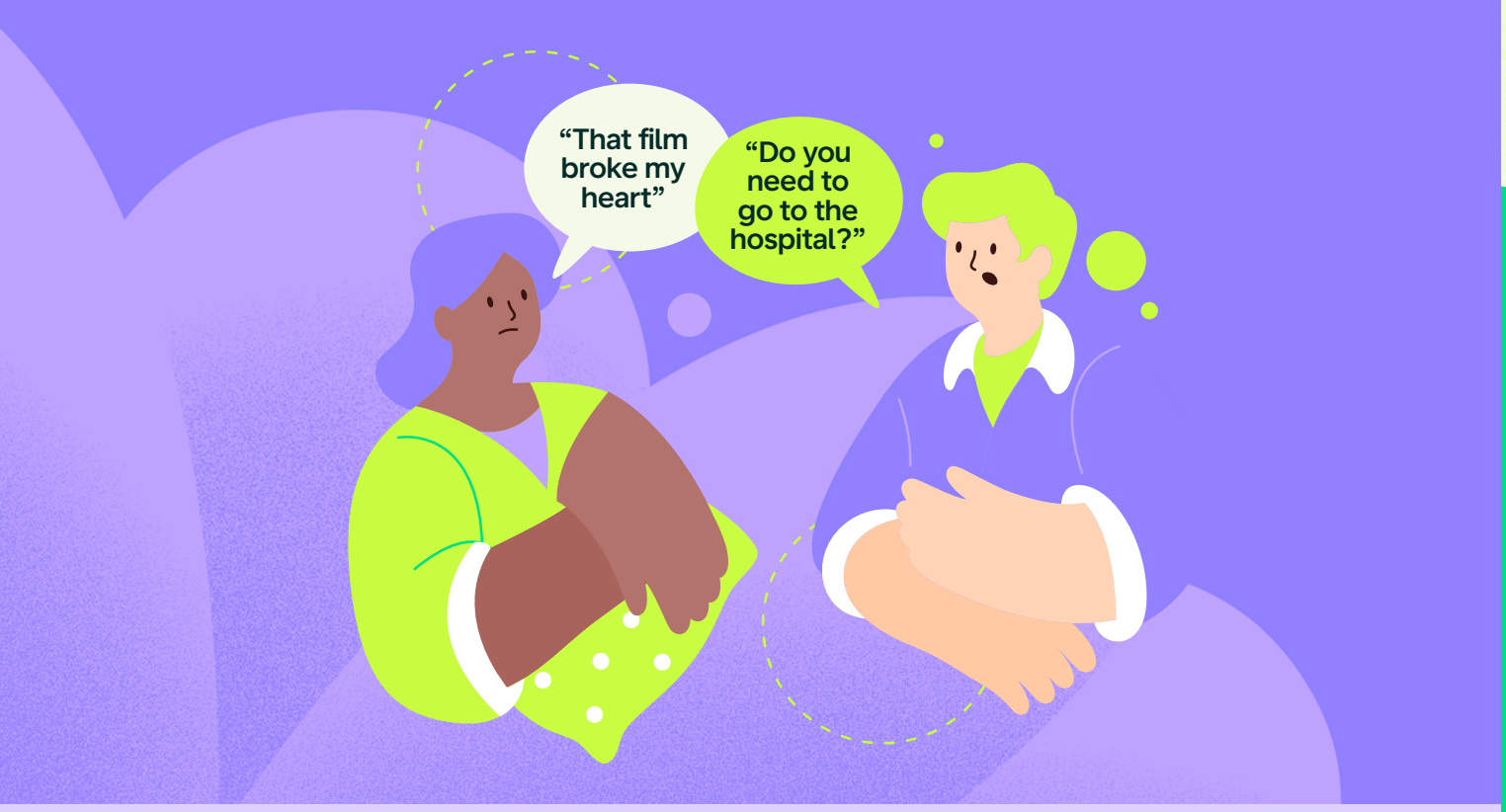
Taking part in rehabilitation can help families comprehend what has happened. It will help them understand why they are seeing changes in their family member. Families can also learn how to adapt things at home, so they can support each other and the person with a brain injury as they regain their independence and learn to adjust.

This section aims to help how family, friends and other people can benefit from learning about what it is like to live with a brain injury and what to say in different situations.

Section Five:

Supporting someone with a brain injury to communicate

Communication is a key ingredient of relationships. But brain injury can change how people communicate.



Difficulty understanding certain phrases

Sam sometimes has difficulty understanding certain phrases, like catchphrases or colloquial expressions.

What can help...

- **Use straightforward words, for example “made me feel sad” is easier for the person to understand than “broke my heart”.**
- **When misunderstandings happen, take the time to explain it to someone with a brain injury.**

Getting confused by too many words

Jane can get confused when people tell her too many things at the same time.

What can help...

- Make sure the person with a brain injury is ready and able to listen.
- Talk about important information in a quiet place. For example, you might need to turn off the radio or TV.
- One person speaks at a time.
- Pause between sentences to give the person with a brain injury time to think.
- Use short sentences with one idea in each. For example: “Let’s go to the shop.” Pause. “We need milk and bread.”
- Write down important words. Use gestures, pictures, objects or drawings to help.

Difficulty speaking clearly

Laura sometimes finds it hard to speak clearly.

What can help...

- Give the person with a brain injury time to speak.
- Take your time.
- Wait for the person with a brain injury to finish what they are saying.
- Turn off the radio or TV.
- Face each other and sit at the same level so the person with a brain injury can see your face easily.
- Encourage the person who has a brain injury to use writing, gestures, pictures, objects or drawings to help get their message across.

Difficulty finding the right words and explaining thoughts

Sam sometimes struggles to find the right words to say what he wants, and to explain what he is thinking.

What can help...

- People can know a word but have trouble saying it. This can be very frustrating for everyone.
- Give the person who has a brain injury time to try and say the word.
- The person may be able to describe what they mean or use gestures, writing or drawing.
- Ask the person who has a brain injury if you can help guess the word.
- If the person with a brain injury becomes very stuck, suggest talking about something else. Let them know that if the word comes later, you can speak about it then.

Getting conversations started and keeping them going

Sam sometimes finds it hard to start conversations, or to keep them going. This may make people think he is not interested.

What can help...

- Pause so that the person with a brain injury has time to say what they want to say.
- Talk about familiar things.
- Use photos, newspapers and magazines to support your conversations.
- Ask "real questions", which ask for unknown information or an opinion, such as "What did you think of the movie?". Avoid questions for which you know the answer, such as "What did we do this afternoon?".

Getting muddled

Sometimes Kate can get muddled when trying to tell things to other people.

What can help...

- Be patient
- Listen to how the other person is feeling through their tone of voice and body language.
- Ask “What happened first?” and “Then what happened?”
- Help the person with a brain injury to practice sharing information.

For example, when they are going to the doctor, the person can write down what they want to say. They can practice telling you the information a few times before going to the doctor.

Difficulty making decisions

Kate sometimes finds it hard to decide.

What can help...

- Take time to talk through decisions.
- Offer the person who has a brain injury a couple of options.
- Write down important points.
- Give them time to talk.

Forgetting things

Sam may forget things other people tell him.

What can help...

- If you have the permission of the person who has a brain injury, set reminders in their phone.
- Write things down.
- Encourage the person who has a brain injury to take notes when they are listening. You may have to pause to let them do this.

Saying inappropriate things to others

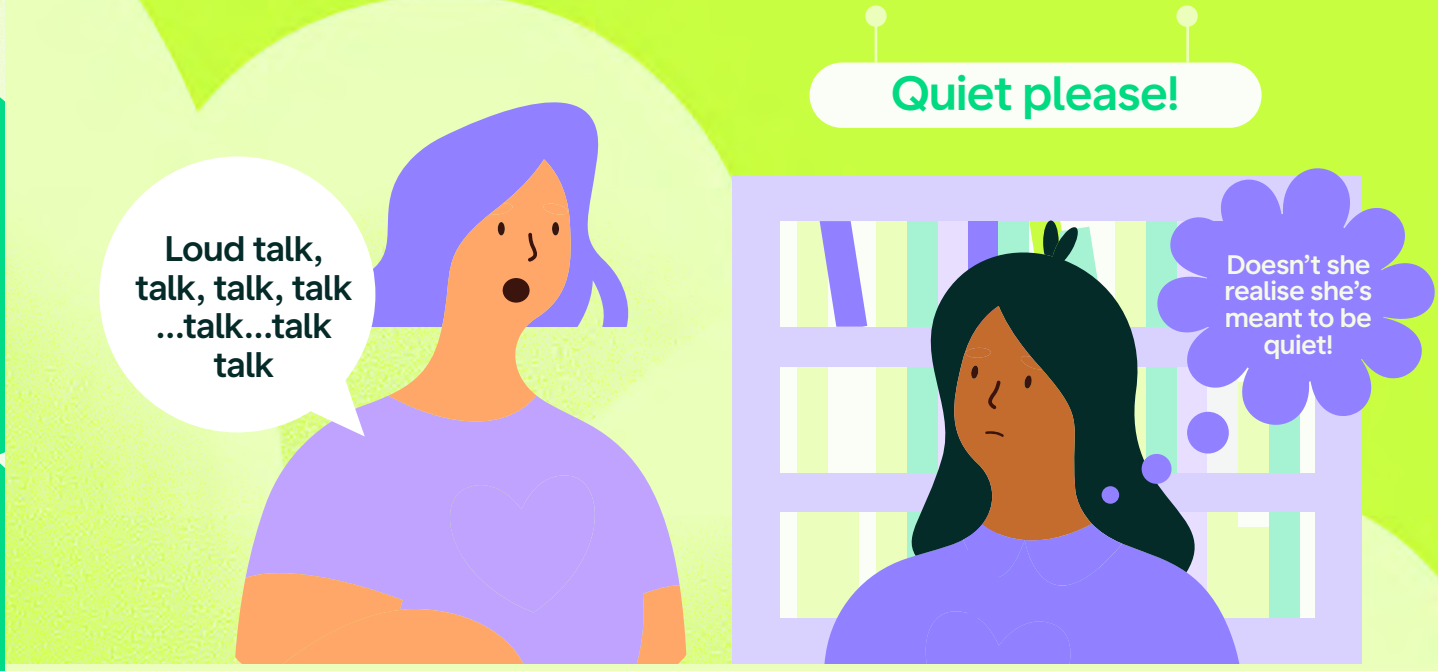
Sam sometimes may say things that cause embarrassment.

What can help...

- **Remember that changes in how people get on with others are very common after a brain injury. Some people have to re-learn social skills. This can take time. It is not the person or their personality. It is a symptom of their brain injury.**
- **Be open and honest with the person about what you are feeling and thinking. Use a relaxed voice.**
- **Talk about the person's behaviour. For example:**

"When you said (pause): 'I haven't had sex for two months' (pause), I felt embarrassed. (Pause) That's something we would talk about in private (pause) with people that are close to us, like our partner."

- **If possible, talk with the person who has a brain injury as soon as something happens.**
- **If possible, use a quiet, private place. Take the person aside.**
- **Suggest a better thing for the person to say. For example:** "When people ask how you are, (pause) you can say (pause) 'A bit frustrated, but it's personal'."



Talking too loudly

Kate may not realise when she is talking too loudly.

What can help...

- **Try to remember that people may have unusual behaviours after a brain injury. They can behave in a way they would not have before. The person does not choose to use unusual behaviours.**
- **Talk with the person as soon as possible. Use a private space and relaxed voice.**
- **Be open and honest.**
- **Talk about the behaviour that feels unusual and suggest other behaviours to use. For example:**

"You're talking in the library. (Pause) It feels awkward. (Pause) In libraries, people are expected to be quiet. (Pause) If you want to talk (pause), we can go to the café."

Difficulty judging space between others

Sam may stand or sit too close to other people.

What can help...

- **Be aware that after a brain injury, someone can behave in a way they would not have before and that may make others feel uncomfortable. The person does not mean to do this.**
- **Talk with the person as soon as possible. Use a private space and relaxed voice.**
- **Be open and honest.**
- **Talk about the behaviour that feels uncomfortable and suggest other behaviour that could be used instead. For example:**

"You are sitting very close to me. (pause) It feels uncomfortable. (pause) Please give me more space."

Not looking at someone when talking to them

Sam might not look at people when he is talking to them.

What can help...

- **You might feel like someone with a brain injury is not listening or paying attention to you, but they may be. This may make you feel like they do not care. It is the person's brain injury that has made eye contact difficult. They probably do care – a lot.**
- **Talk with the person as soon as possible. Use a private space and relaxed voice.**
- **Be open and honest.**
- **Talk about the behaviour that makes you feel like they do not care and suggest what the person could do differently. For example:**

"I'm speaking, and you are looking at the TV. (Pause) It feels like you are not listening. (Pause) It feels like you don't care. (pause). Please look at my eyes when I'm speaking."

Further Reading

My Parent Has a Brain Injury
Johnson, J. (2011), Real World Publishing.

My Mum Makes the Best Cakes
Johnson, J. (2017). Routledge.

My Dad Makes the Best Boats
Johnson, J. (2013) Routledge.

Websites

I'm still me – The day Herbie bumped his head, Speech Therapy Northeast

Video: www.youtube.com/watch?v=328J0E8vq9g

e-book: infograph.venngage.com/pl/kkhekf30Xgw

This section looks at the more hidden effects of brain injuries and ways to improve your wellbeing.

Section Six:

Supporting people's health and wellbeing after a brain injury

Living with a brain injury can be overwhelming at times and it is common to feel anxious or depressed.

Sleep after brain injury

What happens when we sleep?

Sleep is often simply seen as a state of unconsciousness when the brain rests. But our brains and bodies are very busy while we sleep.

There are different stages and cycles that repeat several times throughout the night. Some of these are deep sleep, while other stages are lighter sleep. In fact, we go through an average of six 90-minute cycles of sleep every night.

Sleep involves many different parts of the brain so getting a restful night's sleep is especially important for people with brain injuries.

What affects sleep?

There are a number of things which affect when people sleep and how much they get. These include genetics, your body clock (known as circadian rhythms), stress, pain levels and medical conditions. When and how much you eat and drink can affect your sleep, as do medications and any substances you take. Your sleep environment can also make a difference to the amount of sleep you get.

For example, if there is light coming into your room in the morning, you may wake up early in the summer months.

What are the positive benefits of good sleep?

Getting a good night's sleep is good for people's health and wellbeing. Studies show that it improves your immune system, and strengthens and reinforces memory, cell growth and healing.

> "It affects my relationships and things with my family. It's slowed them right down. You have to be careful what you say."
>
> Male, 17 years.

What are the negative effects of poor sleep?

Sleep is important for everyone. Not getting enough sleep can affect your health and wellbeing, whether you have a brain injury or not. People with chronic sleep disorders are more likely to have physical health problems, such as cardiovascular disease, stroke and obesity. Sleep deprivation has also been shown to cause poor cognition, including difficulties with attention, learning and decision making.

Other studies show a link between sleep loss and poor mood and feelings of tension, frustration and anger. This may explain why we often feel irritable and snap at people when we are tired. Poor sleep can also have a significant effect on someone's mental health, especially anxiety and mood.

It is important to get enough sleep if someone is having brain injury rehabilitation. Not getting enough can affect someone's rehabilitation and may mean it takes longer to rebuild skills and become more independent.

How might a brain injury affect sleep?

Sleep problems are one of the biggest issues for people with brain injuries. Studies show that up to seven in 10 people with brain injuries have sleep problems. There are a range of factors that can affect how much and well someone sleeps.

Like many other aspects of brain injury, the location of the injury can affect the type and severity of sleep problems a person may experience. This is because sleep involves different parts of the brain. Sleep problems can be related to the injury. For example, damage to the parts of the brain that control sleep. But sleep problems can also be related to the difficulties experienced after a brain injury. For example, if someone is experiencing anxiety, depression, pain or tiredness.

(Abrahamson, V., Jensen, J., Springett, K., & Sakel, M. (2017). *Experiences of patients with traumatic brain injury and their carers during transition from in-patient rehabilitation to the community: a qualitative study.* Disability and Rehabilitation, 39(17), 1683-1694. https://doi.org/10.1080/09638288.2016.1211755)

Sleep problems that affect people with brain injuries include:

Insomnia

This is when someone persistently finds it difficult to fall or stay asleep. This condition affects one in three adults in the UK. But insomnia is more common in people with brain injuries. There are certain conditions that must be met for an "official" diagnosis of insomnia. This includes:

- **Difficulty getting to sleep or maintaining sleep.**
- **Early wakening.**
- **Non-restorative sleep, despite having good sleep habits.**
- **Impaired daytime functioning, such as poor concentration, changes in mood, or fatigue.**

The NHS has a useful self-assessment tool to help you figure out if you have a sleep problem. This is available at: **www.nhs.uk/conditions/insomnia/.**

Hypersomnia

This is when someone is extremely sleepy during the day. It is estimated that one in three people with brain injuries may develop hypersomnia.

Nightmares

Unpleasant or disturbing dreams are associated with negative feelings, such as fear or anxiety, and can disrupt sleep. Almost half (45%) of people in the UK have at least one nightmare over a two-week period. It is estimated that one in three people may start having nightmares after a brain injury.

Sleep apnoea

This is when someone's breathing repeatedly stops and starts while sleeping. It is potentially dangerous as it reduces the amount of oxygen going to the brain, which can cause or worsen a brain injury. It is estimated that one in four people who have a brain injury may develop sleep apnoea.

Three main types of sleep apnoea:

- **Obstructive sleep apnoea, which is when the throat muscles relax.**
- **Central sleep apnoea, which is caused by the brain not sending the right signals to the muscles that control breathing.**
- **Mixed (or complex) sleep apnoea, which is a combination of obstructive and central sleep apnoea.**

Narcolepsy

This is when a person suddenly falls into deep sleep at inappropriate times. It is thought to affect fewer than one in 10 people with a brain injury.

Sleepwalking

This is when someone walks around or carries out activities while sleeping. It is rare, with international research finding that fewer than one in 10 adults (4%) sleepwalk. There is limited research on sleepwalking after a brain injury, so it is unclear whether having a brain injury may increase the risk. But amnesia and disorientation that occur after a brain injury can cause night wandering. This is when people walk around when they are awake, and it may resemble sleepwalking.

Bruxism

This is when someone grinds or clenches their teeth while sleeping. It is estimated that up to one in 10 adults have bruxism, but it is unclear whether people with brain injuries are more likely to develop bruxism.

Top tip

People who are experiencing persistent problems with sleep should contact a medical professional such as a GP.

> “I’m sure if I could just get over this sleep thing. It wears you down, you know? Last night I think I went to sleep about half nine and I got up at quarter to nine, and I’m still tired.” Female, 67 years, cited in Abrahamson et al., (2017)

What is a sleep cycle disorder?

Sleep cycle disorders are disruptions to someone’s body clock, which is an internal mechanism that tells you when to sleep and when to wake up. The cycle repeats every 24 hours.

Sleep wake cycle disorders include:

Periodic limb movement disorder
This is repeated involuntary cramping and twitching of the limbs that disrupts sleep. It should not be confused with restless leg syndrome (see below). It is estimated that one in five people with brain injuries may have periodic limb movement disorder.

Restless leg syndrome
This is an irresistible urge to move the legs while asleep. It may cause uncomfortable sensations in the feet, calves and thighs.

Delayed sleep phase syndrome
This is when a person’s sleep is delayed by at least two hours beyond what is considered an acceptable bedtime, which then leads to difficulty waking up in the morning. It is thought to affect one in 10 people with brain injuries.

Irregular sleep wake pattern disorder
This is when a person has no regular circadian rhythm and their sleep and wake times show no clear pattern. This means that rather than sleeping at night, people might have a series of naps over a 24-hour period. Fewer than one in 10 people with a brain injury are reported to have irregular sleep wake patterns.

Managing sleep problems

There is no “one-size-fits-all” approach when dealing with sleep problems after a brain injury. What works for one person may not work for another, and many people find that a combination of different strategies works best for them. The process of tackling sleep problems often involves trying different solutions, so it is important to be patient.

Theadom, A., Rowland, V., Levack, W., Starkey, N., Wilkinson-Meyers, L., & McPherson, K. (2016). Exploring the experience of sleep and fatigue in male and female adults over the 2 years following traumatic brain injury: a qualitative descriptive study. BMJ Open, 6(4), e010453. http://dx.doi.org/10.1136/bmjopen-2015-010453

Professional help

There is no need to suffer in silence. A GP or rehabilitation professional can help with sleep problems or make a referral to a sleep specialist. They can also recommend ways to help improve people’s quality and quantity of sleep, such as relaxation techniques. In some cases, they may prescribe medicine.

Exercise

Exercise has been shown to improve sleep in adults by reducing the time it takes to fall asleep. Taking up a sport, going on a walk or doing activities to get moving might help (please see the section about How a brain injury can affect what someone is able to do). Physiotherapists can recommend activities that are safe for someone to carry out after a brain injury.

Mindfulness and relaxation techniques

Breathing exercises, guided imagery (which involves focusing the mind on positive images) and relaxing your muscles, are techniques which have been found to improve sleep. They work by clearing the mind, releasing tension and relaxing the body. There are resources available to help people practise these techniques, including apps and videos on social media. Some people find that it is helpful to track the effectiveness of relaxation techniques by using a monitoring device, like a Fitbit, Apple Watch, or other fitness monitor or app that can track sleep.

> “Sit down, have a cup of tea and a lie down or snooze, except, trouble is, that sometimes, a snooze turns into a two-or-three-hour sleep or partial sleep, not proper sleep. But then that’s probably not good because you end up waking up half way during the middle of the night.”
>
> Male, 54 years

Sleep hygiene

"Sleep hygiene" refers to habits and behaviours people have around sleep. For example, staying up at night, drinking coffee late in the evening, or taking frequent naps during the day, are all examples of poor sleep hygiene.

Here are nine tips to help develop good sleep hygiene:

1. Create a regular sleep routine. For example, go to bed and wake up around the same time each day.

2. Create a sleep ritual to help relax before bed. For example, have a bath, read a book, listen to music or a podcast, or meditate before going to bed.

3. Get the recommended amount of sleep. Research suggests that people aged 18-64 should get seven to nine hours of sleep a night, and those over 65 should have seven to eight hours.

4. Create an environment that encourages sleep. Earplugs can be useful to block noise. Blackout curtains, blinds or sleep masks can help to block light.

5. Create a comfortable setup. Choose a supportive mattress and good quality bedding as well as loose clothing. It is usually easier to fall asleep when we are relaxed. Some studies also suggest that wearing socks to bed can help people to fall asleep as it regulates body temperature

6. Avoid exposure to artificial lights from digital screens close to bedtime. This includes mobile phones, tablets, laptops and televisions. These screens emit blue light, which tricks the brain into thinking it is daytime. If it is not possible to avoid using digital devices, switch on the blue light filter or night-time setting. This can reduce the amount of exposure to blue light.

7. Reduce the amount of caffeine and nicotine you have close to bedtime.

8. Avoid taking naps too close to bedtime.

9. Avoid drinking alcohol. This might seem counterintuitive, as alcohol is a known sedative which can decrease how long it takes to fall asleep. But alcohol also decreases the amount of rapid eye movement (REM) sleep people get and it disrupts sleep cycles.

The hidden effects of a brain injury

The effects of a brain injury are different for everyone. The physical effects may be visible. These are described in more detail in the Physical effects of brain injury section of this guide. But a brain injury can also cause difficulties that may not be immediately obvious. Family and friends may not be aware of them, or even the person who has the brain injury.

"After my accident, expressing and caring for myself was hard. My mood and emotions were affected, making it difficult for me to socialise. With the help I have received, my weight, sleep and mood has improved so I feel healthier. I am feeling good and enjoy socialising with other people."

Paul had a road traffic accident in 2014 which left him with life-changing injuries. He moved to Ty Aberdafen to get help with relearning life skills and managing his emotions.

These "hidden" effects will be influenced by the type, location and severity of brain injury someone has. It is important to remember that you cannot control how a brain injury affects you. But you can manage how it affects you through treatment and adopting strategies.

Problems with thinking and memory

A common effect of a brain injury, especially for someone who has a traumatic brain injury, is "executive dysfunction". This term is used to describe difficulties with cognition, which are processes such as thinking, memory and problem solving. These affect how we behave, make decisions and communicate. This is also called "dysexecutive syndrome" or "frontal lobe syndrome".

Executive dysfunction is common with injuries that affect the frontal lobes of the brain, which are located behind the forehead. It may also happen when there is not direct injury to these areas. This is because the frontal lobes are connected to many other parts of the brain. Each person will be affected differently and not everyone will have problems with executive dysfunction after a brain injury.

Executive dysfunction can cause someone to:

- **Struggle with social interactions, including not knowing what to say, or behaving in a way that may be seen by others as inappropriate.**
- **Do things on impulse, without thinking them through.**
- **Have difficulty managing emotions**
- **Have problems with initiating and keeping track of activities.**
- **Have memory and attention problems, which may cause people to miss appointments or repeatedly ask the same question.**
- **Have difficulties with abstract thinking and planning.**

These difficulties are likely to affect someone's interactions and relationships with the people around them, as others may find these behaviours inconsiderate or frustrating. Often there will not be any visible signs of injury, so people may not realise someone has a brain injury.

People may mistakenly assume that the person with brain injury is deliberately "acting out" or they are unmotivated or antisocial. This may make them feel isolated, confused, angry or distressed.

> "My short-term memory was affected when I had my brain injury. I couldn't remember things like where my door keys or handbag were. I couldn't remember anything. I hit the left side of the brain, so that's all the memory, speech, language and maths. Now, my memory is a lot better, but it is still developing."
>
> Emma Rich, who introduces this guide

What can help?

It is important to understand how a brain injury has affected someone's cognition. This will help the person to adjust to and manage their difficulties. A full assessment by a clinical neuropsychologist is often recommended. You can get a referral from a GP by explaining the person's history and any concerns.

Depression

Everybody experiences sadness or low mood from time to time. But this should not be confused with depression, which is much more debilitating than “feeling down”. Depression is sometimes described as a feeling of sadness or hopelessness that does not go away with time, and which people cannot control.

Signs and symptoms of depression are:

- **Persistent sadness and low mood.**
- **Feeling hopeless and helpless.**
- **Poor motivation or interest in doing things, even things that used to be enjoyable.**
- **Feelings of anxiety and worry.**
- **Thoughts about ending one’s life.**
- **Lack of energy.**
- **Increased or decreased appetite.**
- **Weight loss or weight gain.**
- **Sleep problems, such as difficulty falling asleep, sleeping too much, or waking up too early.**
- **Reduced sex drive.**
- **Isolation and avoiding significant others, such as friends or family.**
- **Avoiding social activities.**
- **No longer taking part in hobbies and interests.**

Depression is one of the most common mental health problems worldwide and can affect anyone. But people with brain injuries are at higher risk of having depression. Changes to the areas of the brain responsible for emotions may make someone feel depressed. Or it may be a reaction to the changes someone is going through, such as reduced mobility, family dynamics and feelings of uncertainty and worry about recovery.

> “At West Heath House, I had sessions with the clinical psychologist. All the assessments and work allowed me to understand where my downfalls are and how I need some support in the future. It has not been easy to do but I have persevered.”
>
> Bill, 51, a former accountant from Walsall, hit his head when having an epileptic seizure.

What can help?

Depression is an illness and should not be ignored. It is important to get help as soon as possible. Brain injury rehabilitation programmes usually include support to manage depression. Sometimes depression can develop several years after someone has had an injury, once they have been discharged from rehabilitation. In this instance, a GP would be able to make a referral to counselling or mental health services. But in some cases, a referral to a specialist brain injury service may be needed. Some standard treatments for depression, such as medication, may not be as effective for people with brain injuries.

Anxiety

Anxiety can be a normal emotional response. But if it affects someone's ability to carry on with their day-to-day life, treatment may be needed. Anxiety disorders are common, but people with brain injuries are at even higher risk. This can happen because of damage to certain areas of the brain that control emotions, or it can be a response to the events that caused the brain injury, such as an accident. Sudden life changes, such as loss of independence and mobility, can also cause anxiety.

Anxiety can affect someone in different ways. People may withdraw from contact with others or refuse to participate in activities. This can leave people isolated and put physical stress on the body, especially when the feelings go on a long time and the symptoms are physical, like heart palpitations.

> **"I suppose right now I'm worried about not being able to work. I worry about if I will be able to get a pension and things like that"**

Someone with a brain injury who took part in a focus group to develop this guide.

What can help?

Anxiety can be managed by:

- **Identifying what triggers can lead to these feelings.**
- **Removing any unnecessary things which may be causing stress, for example resolving tension with family or trying not to push yourself to do activities you used to do too soon .**
- **Developing and maintaining structured activities or daily routines.**
- **Confiding in someone you trust, so they can understand what you are going through speaking about anxiety can make you feel less anxious.**
- **Taking part in an enjoyable activity, such as exercising, watching a film, or listening to music.**
- **Seeking advice and support from a GP, rehabilitation practitioner or counsellor.**

> **"Having control in life is really important. Coming here [to inpatient rehabilitation], you worry about not getting that control."**

Someone with a brain injury who took part in a focus group to develop this guide.

Anger and irritability

Anger and irritability are common after a brain injury. Someone might feel angrier and more irritable than before. These feelings can show in different ways, including having a “short fuse” and being aggressive, such as hitting, throwing things or yelling.

Anger and irritability can be a response to the changes someone experiences after a brain injury, such as frustration with recovery and rehabilitation, or being more dependent on others. A brain injury may also affect the parts of the brain that process emotions. This means people may not be able to recognise or control their own emotions.

Outbursts can be difficult for the person who has a brain injury and their family and friends. Sometimes people do not realise that these behaviours are a symptom of brain injury, not a choice. Left unchecked, anger and irritability can affect relationships and stop people from socialising. This can cause further feelings of isolation and frustration.

Someone might also feel angry and irritable when they leave rehabilitation and have more ability to process what has happened to them.

What can help?

There are different ways for people with brain injuries to manage feelings of anger and irritability. These include:

- **Identifying what triggers anger and finding ways to manage this.**
- **Practising simple relaxation techniques, such as deep breathing.**
- **Finding alternative ways to communicate.**
- **Going for a walk.**
- **Taking a break.** For example, if feelings of anger and irritability come up during a conversation, revisiting the topic when both parties are calmer may help.
- **Trying not to take anything personally.**
- **Establishing clear rules for communication.**
- **Seeking advice from a GP, rehabilitation professional or counsellor.**

> “I’ll never be 100% but I would like her [partner] to know when I am normal and when I’m not. They seem to think it’s a one-track thing. They don’t see that I’m coming back to my normal self. I’m not like that all the time.”

Someone with a brain injury who took part in a focus group to develop this guide.

Emotional dysregulation

Emotion dysregulation is when someone has sudden and often exaggerated changes in mood. It can happen when areas of the brain involved in processing and regulating emotions and behaviour are damaged.

Mood swings may not appear or feel rational and can happen for no reason. For example, a person might burst into laughter or cry out the blue, and this may not always fit with the situation. Sometimes the person may swing from one extreme to the other.

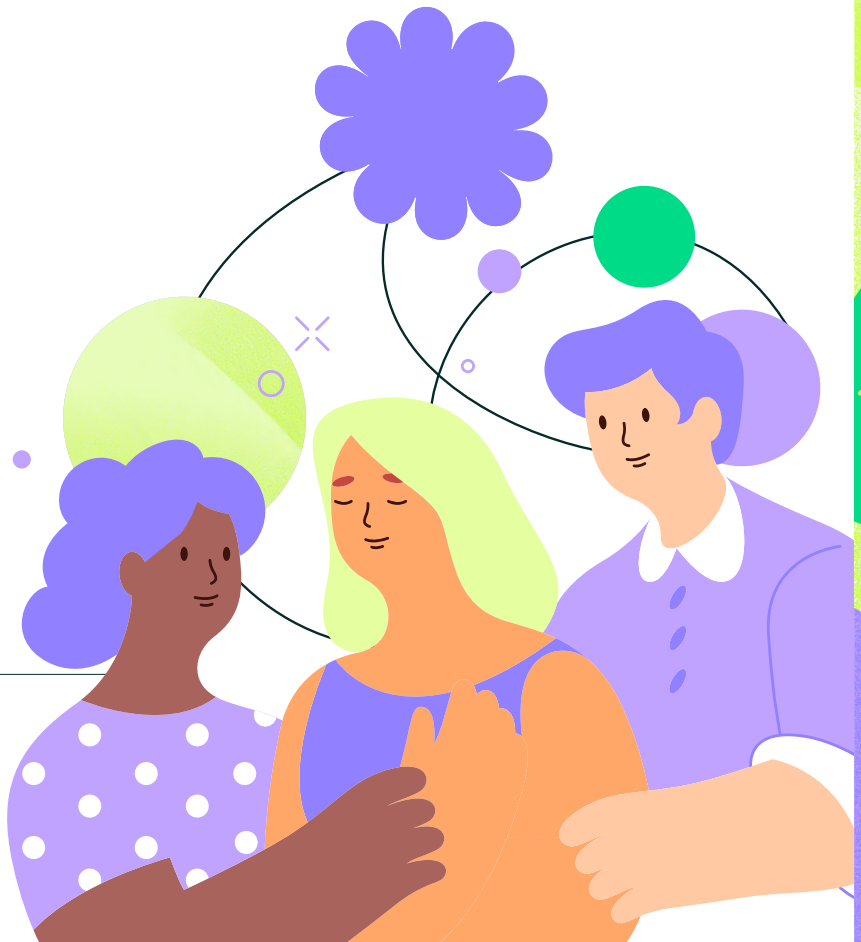
In some cases, the person may not even be feeling the emotions their behaviour suggests. For example, someone could be laughing but be feeling sad.

This can be frustrating for the person with the brain injury and may put them off socialising with family and friends. This may affect their relationships and lead to further feelings of frustration and isolation.

What can help?

There are different ways to manage emotional dysregulation, including:

- **Confiding in people you trust, so they understand what you are going through and can support you**
- **Trying not to assume you know the cause of sudden changes in emotion or behaviour**
- **Trying to remain calm and allow the person space and time to work through what they are feeling and regain control**
- **Letting an incident go and not dwelling on it**
- **Being understanding and non-judgemental**
- **Seeking advice from a GP, rehabilitation professional or mental health professional.**



Luwam's story

Luwam, 31, who has Wilson's disease which can affect the brain, spent around two years at Daniel Yorath House before moving on in October 2020.

> **"Everything changed when I had my brain injury. One minute everything was good. I was happy and having fun, dancing and living life. Then I felt sad a lot. I was really struggling with lots of things."**

"I pushed my friends and support staff away and used to cry a lot. I lived alone and wasn't eating properly or taking my medication. I found it hard to walk and talk and work with people. I struggled with my emotions. When I was sad, I was really sad."

Ups and downs

> **"At Daniel Yorath House, the socialisation helped. I would sit and chat with other residents when I had free time."**

"I did sessions with my clinical team, physio and attention process training. They helped me with talking and walking. Sometimes it has been hard. Sometimes it has been good. Now, my walking is better if I can manage my emotions."

"I control them much better and can cope with people. I am doing really well in supported living. I have been keeping up with my exercises, going on walks and doing yoga and meditation. I use strategies I learnt at Daniel Yorath House to help with my speech, like slowing down and tapping out syllables. I think the work that I have done will help me.

The future is exciting. I am going to do loads of things on my own and have my own peace. I am working on my walking. I am going to study and keep going to the gym."

Enjoying sex after a brain injury

Sex is an important part of life. It gives people fulfilment and helps them to form intimate connections with others. Having a brain injury can affect a person's sex life. This often becomes apparent when someone is going through recovery and attempts to have sex again. One of the common problems people with brain injuries have is loss of libido. Weakness and altered sensation in the body can make it difficult to become aroused and reach orgasm, which can make people lose interest in sex.

The causes of these issues may be physical, cognitive (such as thinking skills), behavioural or emotional. We explore these below:

Physical difficulties with sex

- It may be difficult for men to get or maintain an erection.
- Women may have problems with lubrication during sex.
- A person with a brain injury may find it hard to find a comfortable position during sex because of pain or weakness in parts of their body.
- Some medications can affect sexual performance, arousal or libido.
- Loss of sensations in the body can affect sexual enjoyment and arousal.
- Hormonal problems can affect someone's sexual performance and enjoyment.
- Fatigue is very common after a brain injury, which is likely to have an impact on a person's energy levels.

Cognitive issues with sex

- Damage to some areas of the brain can affect a person's ability to read other people's emotions or understand how they are feeling. Empathy is an important part of developing and maintaining relationships with other people, including having sex.
- Brain injuries can affect a person's motivation and ability to initiate sex.
- Communication skills are an important part of sex. A brain injury can affect people's ability to make their needs and preferences known, and to understand their partner's needs.
- Attention and concentration difficulties may make it hard for a person to focus on a partner or have sex.
- Difficulties with memory may affect a person's intimate relationships as they may have problems remembering a partner's likes and dislikes. They may also have difficulty remembering their own sexual history and experiences, which can affect their sexual identity.
- Some people may not be able to consent to sex and understand the potential risks and consequences, such as sexually transmitted diseases and pregnancy.

Behavioural difficulties with sex

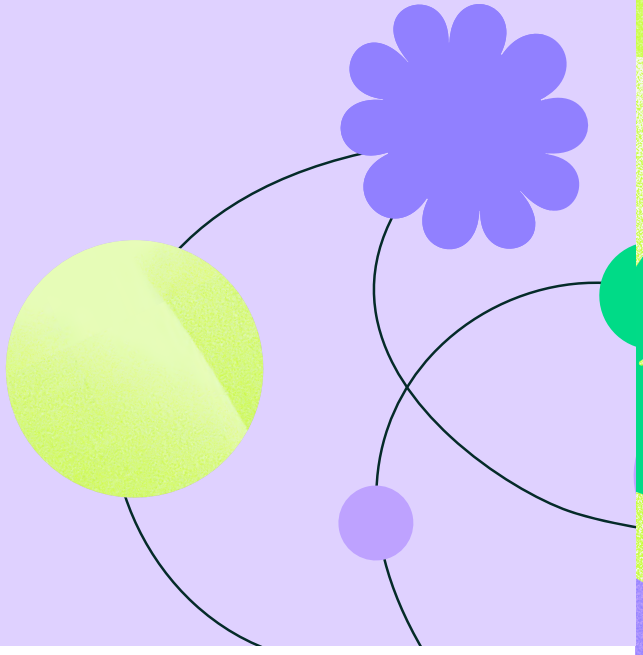
- Damage to some areas of the brain – particularly the frontal lobes – can make someone disinhibited and act inappropriately. Current partners may describe a change in personality, which they may not find attractive. They may find some behaviours rude or unacceptable. Potential new partners can find these behaviours off-putting.
- The person may be more irritable or less attentive to their partner because they have fatigue or cognitive difficulties, which are caused by the brain injury.

Psychological difficulties with sex

- Some people with brain injuries may have anxiety or depression, which can affect their interest in sex.
- Loss of self-esteem and changes in body image can affect people's confidence to initiate sex with their partner.
- Concerns about performance and physical attractiveness, stress and strains within the relationship, and the psychological impact of going through such a huge life event can make it difficult for men to get and maintain an erection. They may struggle to relax and enjoy sex.
- Some people with brain injuries require support with personal care, which may be provided by their sexual partner. This can affect how they feel about each other.
- There may be complicated feelings of guilt, confusion and frustration between partners that can interfere with sex and intimacy.

Tips and information for enjoying sex after a brain injury

- Experimenting with masturbation may help to work out the underlying causes of sexual problems.
- It is important to set time aside for communication and for exploring sex and sexual issues with a partner.
- Consider other forms of intimacy, other than sexual intercourse, such as kissing, caressing or masturbation.
- Explore different positions to have sex in, and consider using mobility equipment, such as chairs, or sex toys.



Getting support from health professionals about sex

For help with any sexual issues, someone with a brain injury can talk to their GP or rehabilitation team. They will be able to offer advice or refer for specialist help.

It is important to find out what is causing the issue, as there may be things that can be done to help. A rehabilitation team or a GP will be happy to have these discussions as sex and relationships are an important part of a person's life. The side effects of medication can be reduced by trying different medications or doses. Any changes should be done with the support and monitoring of a GP, consultant in rehabilitation medicine or neuropsychiatrist.

A GP may be able to carry out blood tests to rule out certain causes, such as hormonal changes. Do share as much information with your GP as you feel comfortable with.

For example, you should tell them about a childhood brain injury as the long-term effects of historical injuries can go undiagnosed. This is especially important if you have changed GP surgeries since then, or if you did not receive immediate medical treatment at the time of your injury.

A rehabilitation team may be able to give advice on sexual positions and help with issues like fatigue, communication or cognitive difficulties. It can also help to consider talking to a clinical psychologist, psychosexual counsellor or sex therapist.

Drinking alcohol with a brain injury

This information has been developed by people with brain injuries who joined an alcohol awareness group at one of our brain injury rehabilitation hospitals. The group spoke about what they thought were the most important and useful messages to get across to other people with brain injuries and their loved ones.

This section also briefly talks about legal and illegal substances.

How alcohol and substance abuse can affect someone with a brain injury

After a brain injury everything changes. Even simple things we take for granted, like having a drink with friends, could have serious consequences for people with brain injuries. Drinking alcohol and taking other substances can affect the brain more because of the existing damage. This could lead to health problems. This can be hard to understand and accept, especially if someone is feeling fed up and wants to go out with their friends.

Drinking alcohol after a brain injury can affect all aspects of life:

Slowing recovery

Drinking can slow recovery. After a brain injury there are fewer brain cells to do the same work, so the brain needs to work harder. After leaving hospital or going through rehabilitation, the brain is still recovering. It takes longer than people might think, so they need to give it time.

Daily activities

Alcohol may make daily activities, such as remembering to take medication, difficult.

Communication

Drinking alcohol may make it harder for people to speak clearly or find the right words, and others may find it difficult to understand them. People may also have difficulty following what others are saying. This can be risky as it can lead to misunderstandings.

For example, a situation could escalate into a fight, or someone might be asked to leave a public place, or the police may be called. People with a brain injury who have not been drinking may also experience this, as others sometimes think they sound like they have had too much alcohol even when they have not.

Concentration and thinking

After drinking alcohol, people with a brain injury may notice that they have difficulty with thinking skills and find it hard to concentrate. They may also get easily distracted. Drinking can make memory worse, and people could lose their phone or money, or not be able to find the way home as a result. Problem-solving skills can also be reduced. Some people may take advantage as a person with a brain injury is vulnerable after drinking alcohol.

Saying what's on your mind

Our brain lets us know when to say the right things at the right time – for example, saying "thank you" after someone has held a door open for us. The brain may not be as good at this after drinking alcohol.

Arguments can get out of hand as someone with a brain injury may not be able to understand what is being said or control their emotions.

Seizures

Drinking alcohol after a brain injury increases the chance of having a seizure, even if the person has never had one before. A prolonged seizure can damage the brain more. Also, medications taken to prevent seizures may not work as well after drinking alcohol.

Low mood

Sometimes a brain injury leaves people feeling depressed or anxious. Alcohol is a depressant and can make someone feel more depressed or anxious and less able to cope.

> "I don't think people realise how bad smoking and alcohol is for our recovery"

Someone with a brain injury who took part in a focus group to develop this guide.

Tips for managing alcohol intake

- Having a brain injury means people need to be more careful about their alcohol intake. They may need to either cut back or stop drinking alcohol. Trying to drink low alcohol drinks or soft drinks instead can help.
- If someone is trying to drink less, avoid situations where drinking is encouraged. For example, if the pub is the person's social hub, they could have a meal there, rather than drinks. Avoid the alcohol section in the supermarket.
- Look for groups or activities that are fun to do when sober. For example, meeting other people with brain injuries at the local Headway group to share experiences.
- Try and listen to friends and family. If someone suggests there's a problem with alcohol, it shows they care.
- Take seizure and mood medications as prescribed.
- Talk to family, a healthcare professional or GP if you are finding it hard to manage your alcohol intake.
- Visit a support group, like Alcoholics Anonymous. Going with a friend or family member may feel helpful.

Legal and illegal highs

It is best to avoid both legal and illegal highs. If someone with a brain injury is taking them, or thinking about taking them, and needs support, they can speak to a GP or other health professional.

As well as substances like synthetic cannabinoids, legal highs can include energy drinks, caffeine and nicotine. These contain chemical substances which produce similar effects to illegal drugs, such as cocaine or cannabis. But they are not covered by current drugs laws.

There is not enough research about legal highs to show they are safe. Legal highs can carry serious health risks.

Effects can include sleep problems (drowsiness and unregulated sleep cycles, for example), seizures, excited or paranoid states and even death in some cases. Even though these are legal and used by many people, they can have a negative effect on health. For someone with a brain injury, they could be dangerous.

Illegal drugs, such as ecstasy and heroin, put people at greater risk because they are harmful to health, with short term and long-lasting effects. They can affect judgement, cause sleep problems, make people feel anxious and paranoid, and kill. People who take them are also breaking the law. Talking to a GP can help people who have problems with illegal highs.

Further reading

General information

- Information Library by Headway: **www.headway.org.uk/about-brain-injury/individuals/information-library/**

How a brain injury can affect someone's sleep

- Top Tips For a Good Night's Sleep by Headway: **www.headway.org.uk about-brain-injury/individuals/brain-injury-and-me/top-tips-for-a-good-nights-sleep/**
- The Best Sleep Trackers Reviewed by the BBC: **www.bbcgoodfood.com/reviewbest-sleep-trackers**
- Sleep Disorders by The Sleep Foundation: **www.sleepfoundation.org/sleep-disorders**
- Healthy sleep tips by The Sleep Foundation: **www.sleepfoundation.org/sleep-hygiene/healthy-sleep-tips**
- Sleep and Traumatic Brain Injury, Model Systems Knowledge Translation Centre: **msktc.org/tbi/factsheets/sleep-and-traumaic-brain-injury#fsmenu6**
- Sleeping Well by the Royal College of Psychiatrists: **www.rcpsych.ac.uk/mental-health/problems-disorders/sleeping-well**
- Guide to Sleep by Netflix: **netflix.com/gb title/81328827** (a joint TV series from Netflix and Headspace with useful information about sleep and mindfulness exercises to help you fall asleep).

The hidden effects of a brain injury

- Managing Anger After Brain Injury by Headway: **www.headway.org.uk/media/3994/managing-anger-e-booklet.pdf**
- Seven Signs of Executive Dysfunction After Brain Injury by Headway: **www.headway.org.uk/about-brain-injury/individuals/brain-injury-and-me/7-signs-of-executive-dysfunction-after-brain-injury/**

Enjoying sex after a brain injury

- **Sexuality and the person with traumatic brain injury: a guide for families. Griffith, E. R., and Lemberg, S. (1993). FA Davis Company.**
- Sex and Sexuality After Brain Injury by Headway: **www.headway.org.uk/media/9623/sex-and-sexuality-after-brain-injury-e-booklet.pdf**

This section looks at living with a brain injury and offers advice and tips on how to manage challenges that may come up.

Section Seven:

Living with a brain injury

Getting back into everyday life after a brain injury can be tough.

From doing activities you used to enjoy, to going back to work, there is a lot to manage and prepare for.

Returning to work or education after a brain injury

Returning to work or volunteering after a brain injury can help people to become more independent. It can provide a sense of purpose and support them to earn an income, which will increase their self-esteem.

Every brain injury is different, and the effects of the injury can vary from person to person. This can make it challenging for people who are considering a return to work. Common effects of a brain injury which may affect someone going back into the workplace include:

- **Physical disabilities**
- **Memory problems**
- **Difficulties with problem solving**
- **Slower thinking**
- **Tiredness**
- **Difficulty concentrating**
- **Planning and organisation**
- **Lack of motivation**

Sometimes people have difficulty imagining how their brain injury will affect them if they return to work. If the person was very good at their job before they had their injury, and it was a key part of their identity, they may feel they will be able to slot back into their job.

It is important to take time to understand any effects a brain injury has had. Healthcare professionals and rehabilitation teams can help people to understand how the effects of a brain injury could affect someone's return to work.

Initially, rehabilitation needs to focus on getting back to normal everyday activities outside of work. Focusing on these activities will help to identify any challenges that may come up in the workplace. Work is often one of the more complicated tasks that people do in their everyday lives and can be thought of as a long-term goal. Many people need time to recover after a brain injury before going back to work and this may take many months. The return to work needs to be a gradual process that is well supported rather than rushed through too soon.

Alistair's story

Alistair was in his late fifties when he came off his bike on his way back from work in 2020. He sustained a severe head injury and was in hospital for six weeks. He then went to Graham Anderson House, Brainkind's independent rehabilitation hospital for people with brain injuries in Glasgow, for 10 weeks.

> **"I trained as a lawyer and was what people would call a 'workaholic'. After leaving Graham Anderson House, I immediately tried to get myself back into work."**

"It wasn't easy at first. I could not remember anything after the accident, and my short-term memory is still horrific. I've got quite a lot of papers on my kitchen table to keep me on track – it's my brain!"

Eyes on the goal

> "While I was in rehabilitation, I was advised that, on average, it takes about two years for people to be able to get back to work again after a brain injury. "

"After my rehab, I was approached by a company that needed someone on a part-time basis. I worked there for a while in a similar role to what I used to have, but this has now come to an end.

Until recently, I had not been very proactive but I was reminded to keep pursuing a job. A conversation with a friend in the pub gave me a second lease of life to persevere. My friend suggested that I looked at alternatives, like working from home. I explained that whatever my new job was, it would have to be an opportunity for socialisation. I think socialising is very important – if you don't use it, you lose it, so you need to keep active."

> "If you have a desire to return to work, go for it!"

How vocational rehabilitation can support someone with a brain injury

Vocational rehabilitation supports people to return to work or another occupation. A rehabilitation team or vocational coach will be able to offer advice about returning to work or gradually testing someone's skills in voluntary work or other community activities. Doing voluntary work offers the chance to get involved in an activity people are interested in and helps them feel useful and productive without the pressure paid employment might bring.

Some employers may keep in contact with an employee who has had a brain injury to find out how they can support them in the workplace.

Sick pay and other benefits

It is important that someone with a brain injury fully understands their sick pay entitlement. An employer will be able to give clear written information about entitlement. Additional information is also available on the government website: **www.gov.uk/statutory-sick-pay**

In essence, people can get Statutory Sick Pay for up to 28 weeks of sickness. An employer might pay more than the statutory amount. This is called "contractual sick pay". If someone's income is reduced while they are off work sick, it may be possible to claim benefits.

Contact the local Citizens Advice for support navigating benefits. There are also online benefits checkers to help find out what people might be entitled to.

Tips for returning to work

There are different strategies that can be used to support someone with a brain injury to return to work. These include:

- **Planning for a gradual return to work.**
- **Altering hours and levels of supervision to build up to someone's usual role or an altered one.**
- **Installing ramps, handrails and other adaptive equipment to improve accessibility for people with physical disabilities.**
- **Using calendars, diaries, dictaphones, alarms, visual prompt cards and notepads to help someone who has difficulties with memory, planning and organising.**
- **Providing someone with a mentor, buddy or co-worker to help with problem solving and easing back into the work environment.**
- **Making sure people with fatigue have regular breaks and flexible working schedules.**
- **Providing a private and quiet working space to improve concentration, as well as setting additional time for tasks.**
- **Setting clear expectations and goals for work tasks that are written down to help keep someone on track and motivated.**

Legislation that employers must comply with

The Equality Act (2010) states that employers must make reasonable adjustments to support the needs of disabled employees. Under this act, people who have a brain injury now have rights that might not have applied to them before.

People with brain injuries should try to be open with employers about the effects of their injury, so they can get appropriate support.

Support can include:

- **Allocating some of the employee's work to someone else.**
- **Transferring employees to another role or workplace.**
- **Making adjustments to the buildings used by the employee.**
- **Being flexible with working hours.**
- **Providing training or retraining.**
- **Providing modified equipment.**

"I used to have a job repairing fences, but I couldn't use the machinery anymore. At York House, I joined a gardening group. It's relaxing and I'm not scared of anything. I'm now able to walk better and cope with my injury."

Sam (not his real name), 53, from Manchester, had a road traffic accident which left him with a brain injury.

Stephen's story

Stephen, who is currently working full-time in finance, sustained a traumatic brain injury in a road traffic accident in 2021. He was admitted to Graham Anderson House, Brainkind's independent hospital in Glasgow two months later, where he stayed for 14 weeks.

> **"Things were a bit difficult at the time I had my accident. I had lost important people in my life. I wasn't really that focused on myself and was feeling a bit down. I went to go see my mother late at night and had taken my bicycle but something happened. "**

I don't have much recollection of the accident but was still conscious when they found me in the middle of the road – my bicycle facing the other way. I was taken to hospital and straight into neurosurgery, where they did a craniotomy [the surgical removal of part of the bone from the skull to expose the brain]. I was then unconscious for about two weeks.

"I spoke to work because I'd made leaps and bounds of progress"

At that point, no one was sure of the chances of me being able to wake up.

I remained in critical care for a month, where there were some complications. I had further brain bleeds. After that, I had two more successful surgeries, but when I woke up, I couldn't speak, I couldn't walk, I didn't recognise people in my family, I couldn't remember that people in my family had died. I had to relearn all of these things. When my rehabilitation at Graham Anderson House started, it was hard. It was all very new to me. A new environment.

Gradually, I started getting into it, and tried to improve myself. I started to fight back and this seemed to make the people who were helping me happy.

Stephen's story

I also wanted to make them happy by showing that it was all working.

All the effort I put in paid off, and I was discharged after three months. At that point, I spoke to work because I knew I had made leaps and bounds of progress.

"Be weak but, in your heart, be strong"

I had an assessment with an external doctor. This had a positive outcome and I was able to go back to work. It has been going well at work. I have learned new things and gained more responsibilities.

Since the injury, I've changed some things, like how I focus on things, and that has enabled me to do better at work.

For example, I listen to a lot of music, which is good for the brain. It activates all areas, and promotes neuroplasticity, which is where your brain tries to build neurons for the first two years after you injured it. I started using parts of the brain that I had never used before and it made connections in a different way.

After an injury like mine, you wake up and don't know what is happening. You can't remember, you feel weak, you feel depressed. You may feel out of it and that there is no way back.

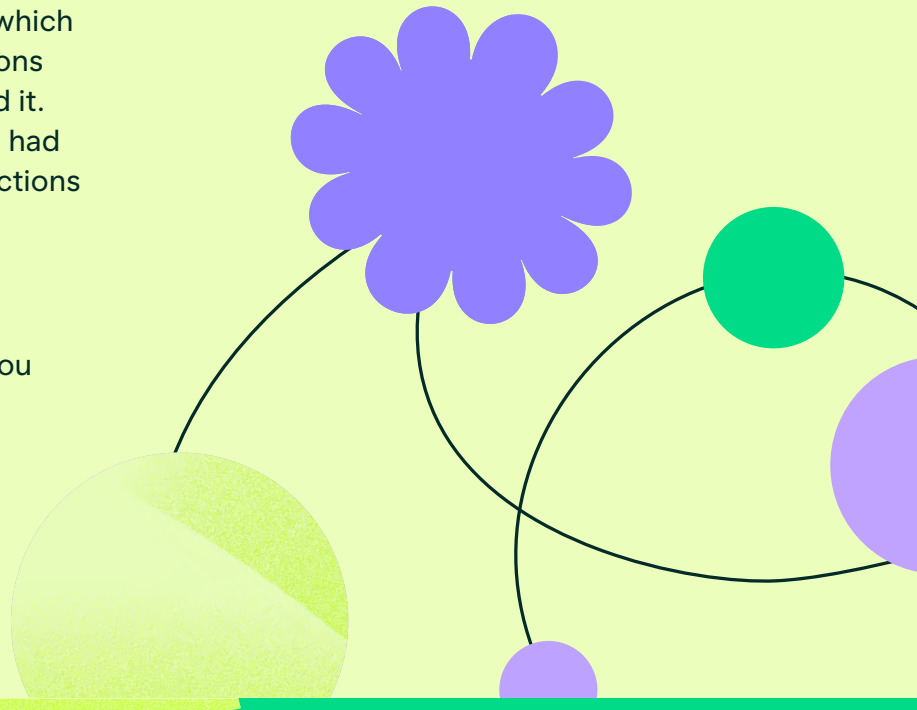
To other people in a similar situation, I would say go with the flow. Take it day-by-day. Listen to the professionals.

The brain is a miraculous thing and it doesn't matter if it looks like the chances of improvement are low. You can win.

Okay, you will go into rehab and might be there for a year – but you might not be. It depends on what you put in, and how much you fight back against what has happened to you.

Fight back against what you can't remember. Be weak, but, in your heart, be strong. You will get there.

You will find a way of getting around it and life can get better.



Volunteering when you have a brain injury

A volunteer is someone who offers free support to another person or an organisation, normally a charity or community-based organisation. Voluntary work can be extremely rewarding. Helping others and doing something productive can increase people's self-confidence and sense of independence.

Volunteering allows the person to adapt to a working routine, usually in a more relaxed way. Working hours are usually more flexible, meaning the person could start by working only a few hours and increase these over time as they develop their skills.

Volunteering is a good way for someone to try something new and discover strengths and skills, or to identify activities and tasks they do not enjoy.

Volunteering may also be a route into paid employment for some people. Some paid roles start as voluntary. Then, in time, after building up some skills and experience, volunteers may be encouraged to apply for paid positions.

> "As well as physiotherapy and speech and language therapy, I do gardening. I also love volunteering at a nearby garden centre."

Jane, 55, who had a brain injury in 2022.

Accessing specialist employment support

Supported employment helps people with disabilities, including those with brain injuries, to find and keep long-term employment. A vocational specialist or job coach will help someone to identify employment opportunities and provide support once they have found a job. They will make sure the person has ongoing training and support in the role.

Getting into education and training with a brain injury

Going back to studying after a brain injury can be a good way to get new skills and qualifications, which may be needed to get a job. It can also provide a sense of purpose.

Academic or vocational learning has lots of benefits including:

- **Gaining qualifications.**
- **Improving knowledge and skills.**
- **Increasing confidence and self-esteem.**
- **Meeting new people and discovering new social groups.**

Some people may find studying full-time challenging because of difficulties with concentration, memory and fatigue.

In this case, course providers may offer the flexibility to study part-time, in the evenings or on weekends, and run online or distance learning courses.

Most colleges and universities have a student services department or a learning support adviser to help students with their studies. Their details can be found on websites of local colleges and other education centres.

How a brain injury can affect what someone is able to do

We all have activities we enjoy doing, whether it is recreational (swimming or walking, for example), something more relaxing, like listening to music, or going out on day trips. These help us to have a balanced lifestyle and promote good mental health.

Taking part in activities is an important aspect of the rehabilitation process for people with brain injuries. It can help them to develop social and interpersonal skills as well as improve thinking and motor skills that are needed to carry out day-to-day movements, such as lifting and writing. Taking part in activities can also provide structure to someone's day or week, giving them a sense of purpose.

> **"I took part in a sponsored 5km run to raise funds for Brainkind. The race marked just over six months since my brain injury."**
>
> Emma Rich, who introduces this guide

Activities that help with enjoying life

Taking part in activities can help people to stay active, meet others and feel part of their communities. This can be rewarding and give people a sense of achievement, helping them to feel good about themselves.

After a brain injury, some people experience a sense of loss for the life they had before their injury. This can cause people to feel lonely and isolated, anxious, unconfident and to lose their enjoyment for life. For more on this, see **section four: Supporting people's health and wellbeing after a brain injury.**

Supporting people with brain injuries to take part in regular activities, whether it is physical ones or practising daily skills, such as cooking, can help them to achieve a sense of identity again. Creating a daily or weekly timetable can help people to feel motivated about doing activities. It can also help them to learn and develop new coping strategies to manage their brain injuries.

Taking part in activities after a brain injury

A common question that people with brain injuries ask is whether they can take part in the same activities they used to. The answer depends on how the injury has affected them, risks to the person and others involved in the activity, and whether any adaptations are needed to prevent risks.

It is important for families to discuss potential risks, and how to overcome them, with health professionals and rehabilitation teams. This will help them to support the person with the brain injury to enjoy the activities they used to do. Local authorities have initiatives in place to support disabled people to take part in sports and other activities they enjoy. Other resources and specialist help can be found through colleges, sports and leisure centres. Have a look at their websites for further information.

> “Before my injury, I was volunteering for earthquake disasters. I can’t do that now, though. I told my daughter I can’t work, but she told me I should be a baker now.”

“The rehabilitation staff are helping me cook. I remember before my wife’s birthday, I made her a croquembouche, a tower of profiteroles. I made it all myself. My wife has a cunning plan for when I get home. She’s going to get one of those food boxes and make me cook food.”

Ian, 45, who had a brain injury in 2021.

Supporting people to take part in activities they used to enjoy before their injury

Sometimes, people with brain injuries lack motivation or have difficulty taking part in leisure activities. This may be because disability is seen as a barrier to the activity, or the person lacks confidence or is anxious about socialising. Here are some ways people with brain injuries can overcome these barriers:

Relaxation techniques and meditation may help someone who is anxious to feel calmer and more focused. There are online resources and apps that can be downloaded onto a mobile phone or tablet, such as Headspace or Breathe 2Relax. In some cases, it may be beneficial to learn how to use these techniques with the help of a healthcare professional. GPs can make the appropriate referrals.

Writing down activities a person used to enjoy before their injury can motivate them to do them again.

Adapting activities can help someone with a brain injury to take part. For example, if someone used to enjoy swimming but cannot get into a pool by themselves, a pool with a hoist facility could be an option. Or using a float or taking a friend or relative to provide support, could help someone to enjoy the water again.

Offering simple rewards can encourage someone to take part in activities. For example, going for a coffee at a favourite cafe after completing an activity could help the person to achieve their goals and aspirations. The reward should be something the person enjoys.

Getting back into driving after a brain injury

Driving is often a big part of someone's identity and key to their independence. So, after a brain injury, people may feel anxious and worried they will not legally be able to drive.

Driving is a skill that requires a series of physical actions and mental processes and coordination of the two. Following a brain injury, a person may experience ongoing difficulties that affect their ability to drive safely.

Physical issues, such as weakness in one side of the body, can often be managed by adapting a vehicle. This may include using an automatic car or hand controls.

It is often difficulties with cognition, such as thinking, memory and problem solving, that can affect driving ability. Driving requires someone to be able to pay attention, monitor their environment, react quickly to any potential hazards and manage frustration.

After a brain injury, some people are not aware of how their cognitive skills have been affected, particularly if they have been in hospital and have not had the opportunity to test out their skills in real life. They may assume they can drive safely.

Letting the DLVA know that you had a brain injury

If someone drives and has had a brain injury, it is a legal requirement to let the relevant licensing authority know, even if the person thinks they are capable of driving. In England, Wales or Scotland, this is the Driver and Vehicle Licensing Agency (DVLA). In Northern Ireland, it is the Driver & Vehicle Agency (DVA).

People can be fined or prosecuted if they are involved in an accident and have not informed the relevant licensing authority of their brain injury. Not informing the authorities would also mean that their licence is not valid and they would not be insured in the event of an accident.

If someone's doctor or rehabilitation team say their injury will affect the person's ability to drive for three months or more, the person must send their licence to the DVLA.

Driving and duty of care

If you are concerned about the driving of a family member who has a brain injury, you can report this to the DVLA.

GPs and rehabilitation teams also have a legal obligation to speak to the relevant licensing authority if they believe a person is not fit to drive.

Fill out a form on the DVLA website to let them know about your concerns. Or you can call them on **0300 790 6806**.

What happens after you have informed the DVLA?

Each person's circumstances are considered individually. But DVLA guidance for medical professionals says that after a serious brain injury, a person who has problems with cognition or vision will need to wait six to 12 months before driving again. For people that hold a special licence, such as bus and lorry drivers, the rules are stricter.

The DVLA usually respond within six weeks if you contact them about yourself or someone you know who has a brain injury. Or they will write to you to say the process will take longer.
The licensing authority may contact the doctor of the person with a brain injury or ask them to go for a driving assessment.

While awaiting further information from the licensing authority, ask the doctor or rehabilitation team of the person who has a brain injury whether they are fit to drive in the meantime.

Once the DVLA has discussed the case with the medical or rehabilitation team and completed any required assessments, they may:

- **Say the person with a brain injury can start driving again.**
- **Ask them to drive an adapted car.**
- **Issue a different type of licence or a shorter licence.**
- **Ask them to stop driving.**

If you disagree with the decision, it is possible to write to the DVLA to show them any new evidence demonstrating that the person with a brain injury is fit to drive. For some people this can be a frustrating process. It is important to stay focused on the rehabilitation goals. Working on becoming more independent and managing cognitive difficulties, such as thinking, memory and problem solving, may help people to get back to driving again.

Once the medical standards to drive again have been met, someone with a brain injury can apply to get their licence back. They may be able to drive in the meantime. That is, provided their doctor or rehabilitation team have said they are fit to drive and the DVLA has received their full application. All forms to reapply for a licence are on the DVLA website.

Contact details for the DVLA

For contact details, please visit:
www.gov.uk/contact-the-dvla/y/driving-and-medical-issues

To find out more about telling the DVLA about medical issues, please visit:

www.gov.uk/driving-medical-conditions

www.gov.uk/browse/driving/disability-health-condition

This section covers some of the most frequent questions. If you have suggestions for other questions that may have occurred to you, please contact Brainkind

Section Eight:

When will I be able to...?

After a brain injury people will have a lot of questions, including about when they will be able to do certain activities.

When will I be able to leave hospital or the rehabilitation unit?

Every person's brain injury is different, so it is difficult to predict exactly when someone can leave hospital. Statistics from the Trauma Audit and Research Network (TARN) indicate that, on average, people stay in trauma centres for nine days, with some requiring stays longer than 18.

Most people with a severe injury will be offered rehabilitation. Results from the UK Research Outcomes Collaborative (UKROC) show that, on average, people stay in specialist rehabilitation for 70 to 167 days. Those that have cognitive behavioural disabilities, which affect how someone thinks and behaves, need more time.

Some people benefit from post-acute rehabilitation. This is when people have been in hospital but are not quite ready to go home. Usually, people leave these services after 84 to 119 days (three to five months).

In total, people may need inpatient services for six to 12 months. However, how soon people recover varies, and depends on a range of factors, including the type of injury someone has and how long ago it happened. The medical or rehabilitation team of someone with a brain injury will be able to advise on individual circumstances.

When will I be able to speak?

Research suggests that two in three people with a traumatic brain injury are able to talk again after six months. However, three in five people will continue to have some problems after this time. The section Supporting someone with a brain injury to communicate in this guide provides useful tips.

When will I be able to exercise?

Movement and exercise support your recovery, so you can start attempting gentle exercise as soon as you are able. Exercise suggestions are available at the end of the section How a brain injury affects someone in this guide. You should avoid any heavy lifting until your doctor says it is okay. Your doctor or a physiotherapist will be able to advise how much you can do and suggest adaptations to suit your individual needs.

When will I be able to dye my hair?

Having a brain injury does not necessarily mean that you can no longer dye your hair. But if you had surgery, you will need to wait four to eight weeks after surgery to allow the skin to heal. Always carry out a patch test before using a permanent or semi-permanent hair dye, even if you are using the same dye you have always used. More information on how to avoid hair dye reactions is available through the NHS at **www.nhs.uk/conditions/hair-dye-reactions/.** Speak to the health team involved in your care to understand what is best.

When will I be able to have sex?

This will depend on how long it takes to recover and how the person with brain injury and their partner are affected. Speak to your GP or rehabilitation professional who will be able to advise and support you. The section **Enjoying sex after a brain injury** in this guide provides more information and tips.

When will I be able to drive?

This will depend on the difficulties each person experiences, and how these might affect their ability to drive safely.

After sustaining a brain injury, the person with a brain injury or someone supporting them will need to inform the DVLA. According to DVLA guidance, those who have problems with cognition or vision will need to wait six to 12 months before they can drive again. The section called Getting back into driving after a brain injury in this guide provides further information. Speak with your GP or rehabilitation professional for help and advice with this process.

When will I be able to socialise?

Going back to work may be a way to meet new people and socialise. But it may take some time for people with brain injury to return to work. Whether you are attending crowded or loud events, or even the quiet darkness of the cinema, you might not react like you did before the injury. For example, you may feel anxious with lots of people around, or might find a bright environment unpleasant. If you tend to socialise over a pint, the section about Drinking alcohol after a brain injury will be useful.

When will I be able to go back to work?

Research suggests that about one in three people return to work within the first-year post-injury, and more than half go back within five years. However, when and how someone is able to return to work will depend on their individual needs.

Research also shows that many survivors of brain injury who return to work, change their job and have an altered employment status. The section Returning to work or education after a brain injury gives more information about the support that is available and how rehabilitation can help.

When will I be able to travel (abroad and within the country)?

This will vary from person to person, but there are a number of things to consider before making plans. Ask your doctor when it is safe to fly. Make sure holiday insurance covers any care or equipment that might be needed away from home. Take enough medication to last for the whole journey. If you are travelling abroad, you will need to check if the medication you need is restricted in the country you are visiting, and what medical documents or letters you may need to take with you if it is.

Consider how easy access to emergency treatment is, in case it is needed. Headway provides additional information about funding and insurance on their website: **www.headway.org.uk/about-brain-injury/individuals/practical-issues/holidays-and-travel/**

When will I be able to get a brain injury identity card?

Before you can get a brain injury identity card, you will need to verify that you have a brain injury, either through a Headway local group or branch, or a clinical professional. As the Headway brain injury identity card is personalised to explain the effects of each person's brain injury and the support they may need, it may be useful to submit an application after a needs assessment.

It will take some time to process the application, around 10 weeks if all the information required is provided.

For example, if the application does not include clinical verification of the brain injury, it will take considerably longer to get the card. To apply, visit **headway.secure.force.com/registrationpage**

This section goes into more detail about the range of support and treatment that is available.

Section Nine:

What support is available for people with brain injuries?

A brain injury changes lives, including the person who has had one and their family and carers. There is a range of support available to support these people, including everything from therapy to technology.

Rehabilitation

When the brain is damaged, its tissue does not fully heal, like skin does when we have a cut. But it can reorganise itself, so that it can recover some of the things it used to do.

Brain injury rehabilitation supports this process of healing. It offers people with a brain injury and their family and loved ones the opportunity to learn ways of coping

Brainkind is a charitable organisation that provides rehabilitation across the UK.

If you, a family member, or someone you know would like to be referred to Brainkind services, please contact the referrals team on 0330 0581 881 or speak with your GP or consultant.

A neurobehavioural approach to rehabilitation

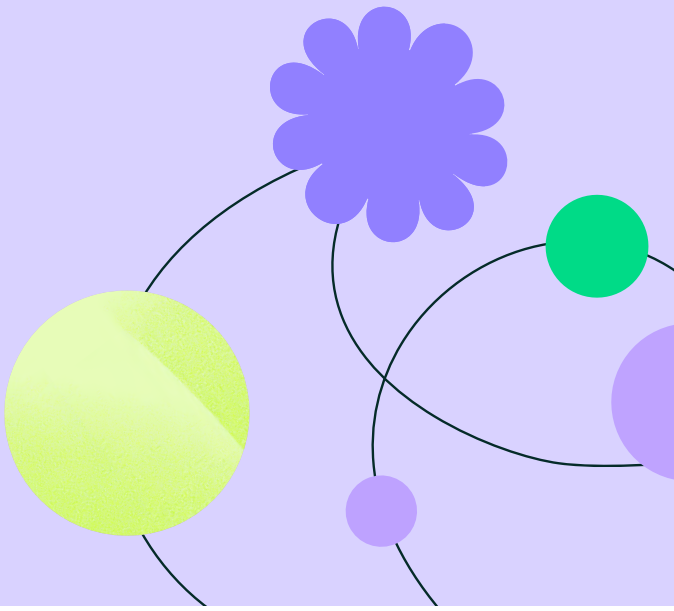
Brainkind uses a neurobehavioural approach to rehabilitation. This combines evidence-based, scientific methods of changing behaviour with an understanding of brain injury. This approach to rehabilitation:

- **Considers a number of factors which can contribute to someone's recovery.** This includes the characteristics of the injury, such as its cause, severity and how long ago it happened, someone's medical and personal history, and their mood and aspirations.
- **Supports people to overcome their problems and achieve their personal goals in a constructive and rewarding way.**
- **Uses a specialist team of psychologists, physiotherapists, occupational therapists, and speech and language therapists.** They workwith someone with a brain injury to help them to become more independent.

Our specialist brain injury tool

Health and care professionals can use the Brain Injury Needs Indicator (BINI) to assess how well someone has recovered from their brain injury and what social care support they might need.

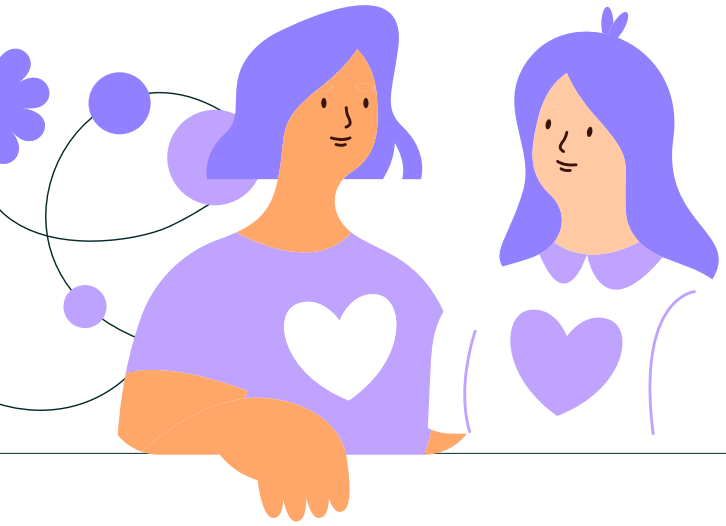
Find out more at: **www.brainkind.org/bini**



Paying for rehabilitation and care

Rehabilitation is usually funded through the NHS or occasionally adult social care. Other funding routes include health insurance, compensation or private funding. Access to funding through the NHS will require a referral from a health practitioner and agreement from a local commissioning body such as an Integrated Care Board.

Social services can help provide care after a brain injury. But the amount of support someone receives depends on what help they need and their eligibility according to the Care Act 2014. The person who has a brain injury may be entitled to a care needs assessment with their local council. The UK government sets out funding rules and the individual may be required to make a contribution towards the cost of their care and support depending on their financial situation. They will have a “financial assessment” to work out what they will have to pay towards the cost of their care. You should contact your local authority to organise this.



Support for carers

The Care Act 2014 is the law that sets out how adult social care in England should be provided.

If you care for someone, under this act, you have a right to have an assessment to see what might help make your life easier. This is called a carer’s assessment. It is free and anyone over 18 can ask for one regardless of the amount or type of care you provide, your finances or level of need for support. It is separate from the needs assessment the person you care for might have, but you can ask to have them both done at the same time.

The assessment will look at how caring affects your life and wellbeing and whether you are able or willing to carry on caring. To get a carer’s assessment, contact adult social services at your local council. Ask them for a carer’s assessment.

Support for families

At Brainkind’s brain injury assessment and rehabilitation centres, people experience a welcoming environment that supports them to continue to have contact with their family. This can have a positive impact on re-building family relationships and rehabilitation itself.

People cope with difficult circumstances in different ways. Some actively seek social and emotional support. Others can isolate themselves to come to terms with the major life changes that having a brain injury can bring. There is no “right” way to do this. People might want to try different approaches to identify the most helpful way of coping with the changes they face.

Support for families from professionals is varied and can include:

Practical support There are services that can help with things like finances and housing. Addressing these practical issues is often necessary before families can begin to discuss their emotional distress.

Education Information about how the brain can be affected may support families and reduce their distress. When families understand and are included in developing strategies to support the person with a brain injury in a healthcare or rehabilitation setting, it becomes easier for them to begin practising these at home.

Social media, film and online resources can be good sources of information and support but not always entirely accurate or appropriate for everyone. So, do speak to health professionals to make sure you are getting the right support.

Support groups Family members will need time to process their feelings. Support groups are often offered in rehabilitation centres and can help families to share their stories with each other. Support groups may also be available in local communities through charities, such as Headway.

See the Further reading section for more details.

Individual support GPs can make referrals to specialist services, like adult or child mental health, if you ask them to. In England, you can access the NHS psychological therapies service (IAPT) without a referral from a GP.

More information about these services is available at: www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/nhs-talking-therapies/.

Family members of someone with a brain injury may also be offered support by a rehabilitation team. This can help them develop coping skills and build their resilience, which will support the person with the brain injury as well.

Therapy It can be difficult to cope when an individual family member challenges “how things used to be”, emotional distress is high or if there are changes in people’s roles. These things can become obstacles to communication.

Psychologists, counsellors and psychotherapists can offer therapy to couples, or the family, to help them communicate in a way that feels safe. Expressing feelings through art, shared projects, or joint problem solving and or planning is often helpful.

Using technology after a brain injury

Technologies enhance what humans can do. Cars mean we can travel further and faster. Email allows us to communicate more. The internet gives us an opportunity to widen our capacity to absorb information. In the same way, technology can be used to allow us to do things that we can no longer do because of injury or illness. This is called assistive technology.

Technologies can take time to learn to use. Finding the right device or software to meet the needs of someone with a brain injury is a process. The first step is showing the person how to use it.

Then, it is about trialling the device in real-life situations and adjusting to it over a period of time.

Below is an overview of technologies that have been used to treat or minimise difficulties experienced by people with brain injuries. Some of the technologies are generally used temporarily to support someone in rehabilitation. Others may be used longer term.

Neuropsychologists and occupational therapists understand what technology might help someone in specific areas so their input can be very helpful.

> “Paul’s life has improved since he started using assistive technology. He can now send an email to his mum and dad, or research the line-up for a festival, whenever he wants.”

“He can control his environment without staff coming in and out to change the TV channel or switch his light off. He is so motivated to do more and the technology he uses is giving him the freedom to do it.”

Stuart, Paul’s Occupational Therapist at Redford Court in Liverpool. He has helped Paul use a device that controls his environment, which is powered by a knee switch, and a communication aid.

How technology can support someone with physical problems

We have used a range of devices to help people with physical problems for a long time, from wheelchairs to Zimmer frames. Now, digital technology has added to the range of things that are available to help someone with a brain injury, including:

- **Apps that read text out loud, which can help someone who has lost the ability to speak**
- **Eye-trackers, voice assistants, or switches that can be controlled with the head or mouth and help someone with very limited ability to move**

- **Devices, called brain-computer interfaces, which link the brain's electrical activity with a computer or robotic limb. These allow someone to control their central nervous system simply by thinking of what they want to do.**

> "I've been using Beamz software and, for the first time, I'm able to make and play my own music!"

Hannah, a resident at Shinewater Court, Eastbourne, which offers a range of assistive technologies to residents.

To learn how to use apps, download this Age UK beginner's guide to using them: **www.ageuk.org.uk/globalassets/age-uk/documents/digital-instruction-guides/a-beginners-guide-to-apps.pdf**

To improve your digital skills, try Vodafone's "Hi Digital" course, developed in partnership with Independent Age: **www.vodafone.co.uk/newscentre/hi-digital/.**

To stay safe online, try the Cyberablity training developed by Dr Kate Gould at Monash University in Australia: **cyberability.org.au/free-training.**

Useful apps

- **CanPlan**
  For planning out tasks
- **MediSage**
  Medication reminder
- **Proloquo2Go**
  Uses images and typed words to help someone speak
- **T2moodtracker**
  Gain insight into your mood
- **Lumosity**
  Brain training game
- **Google Calendar**
  An online diary
- **Headspace**
  A mindfulness app
- **Breathe2Relax**
  Breathing exercise to manage stress

For more apps, please visit **www.my-therappy.co.uk,** an NHS website that describes and reviews apps for people with a brain injury or other neurological conditions.

How technology can support people with cognitive difficulties

A brain injury can affect different cognitive functions. Some technologies can help with this during and after rehabilitation. Many of these technologies are interactive and learn things about the person using them and their surrounding environment.

Paying attention

We use technologies to make us pay attention all the time. Everything from the cash-dispenser machine that beeps if we do not promptly retrieve our bank card after we have collected our money.

To lights that flash on our car dashboards to warn us when we are dangerously low on fuel. Similarly, technologies can be used to help someone with difficulties paying attention after they have had a brain injury.

These include:

- **Audible alerts that act as a cue to think about what someone is doing and to remember their intentions.** Watchminder, a wristwatch that can vibrate as a reminder to do things or Motivaider, a vibrating pager-like device, can do this. A smart phone can be used in a similar way. Motivaider is also available as an app.
- **Apps that help with attention can be found on mytherappy.** This is an NHS website that describes and reviews apps for people with a brain injury or other neurological conditions.
- **Cognitive training on a computer which asks people to carry out a number of tasks connected with memory or attention.** This is most effective when it is used as part of a comprehensive rehabilitation programme. This training might work because it increases the brain's capacity to process information. It could also help increase someone's stamina and confidence.

Did you know?

Research shows that listening to preferred music can increase someone's level of consciousness after a brain injury. Music can also make people sit in a more upright posture, which helps improve attention. It is best to use instrumental music to improve attention, as words can take our attention from the task in hand.

Remembering

Remembering to do something in the future is called “prospective memory”. Most of us use low and high-tech devices to assist with prospective memory. This might be putting appointments in a diary or post-it notes on the fridge. As well as writing reminders down on paper, we can use technology to help us remember things.

To help someone with a brain injury with remembering, the following technology is available:

- **A mobile phone** can alert someone with memory problems to the things they want or need to do.
- **Neuropage** is an electronic paging system which sends messages to remind people to carry out an action, like taking medication, or going to a doctor’s appointment. This service is now provided by Autopage.
- **Google Calendar** and other similar apps can be programmed to send reminders about things someone needs to do.
- **Smart assistants, like Alexa,** work well for those who prefer to receive voice-messages. You can use your voice to set the reminders. The reminders will then be spoken by the device.

Planning and monitoring

Giving someone a reminder to do something, like taking medication, may not be enough. Sometimes, people with a brain injury need help to remember how to do it. Like how much medication to take, or how to prepare it. It is important to help someone remember what the next step of a complex task is. The process of guiding someone through all the steps of a task is called ‘micro-prompting’.

Research suggests that micro-prompting devices or software can help people carry out daily tasks, like making a cup of tea, on their own, making sure important steps are not missed. For example, technology that helps with this might ask: “Have you got a cup?”. If the person says “Yes”, it might say “Okay, now get a tea bag”. The information might be complemented by pictures on a screen.

Evidence shows that these technologies can be very effective. It is important that these technologies are set up to someone’s individual needs and preferences. For example, some people might find pictures helpful. For others, pictures might mean the person may pay less attention to what they are doing.

Finding your way around places is a key skill for independence but sensory or cognitive difficulties can get in the way of reading maps. Digital maps or location apps are really useful for everyone, including people with brain injuries.

These can easily be put on an audio setting so the instructions are read out when you are walking, and you can use headphones to hear the directions discreetly. These technologies can also tell us which public transport to take and when.

How technology can support someone to feel calmer

Understanding how our body is responding to feelings of anxiety, anger and aggression can help us feel better. Devices and apps which analyse our heart rate and tell us what it is can help to identify these kinds of emotions. Then we can manage these feelings through guided breathing, following visual cues such as lights rising and falling on a screen, for example.

This kind of technology is often incorporated in smart watches or fitness monitors. But specialist devices might be needed for someone with a brain injury. So, it is best to speak to a rehabilitation professional.

How technology can motivate people and help them manage their time

When you cannot get going with an activity, it is called “initiation deficit”. Technologies that allow you to set time- or event-based reminders can help with this. For example, someone might programme a device to remember to do something “before going out”.

Scheduling devices or software can also help people who find it difficult to think of things to do. People can plan activities in advance and set alerts for these at the appropriate times. Digital calendars will warn us if we try to set two appointments at the same time. If location information is available, the technology can even advise us when it is time to leave the house to make it to an appointment on time.

New technologies

Brainkind is always looking for new technologies that can help support someone’s rehabilitation and increase their independence. Collaborative work between people who have a brain injury, their support networks, technology developers and healthcare professionals, will produce more assistive technology that improves people’s lives.

These include:

- **Apps that can recognise text and name people, colours or objects, by pointing the device camera towards a target, or a photograph. This is invaluable for people who have problems recognising things visually.**
- **Robotic systems that help someone to move. These could be life changing for people with limited movement following a brain injury.**
- **Smart homes are houses fitted with sensors that interpret what is happening in the environment, and act, or prompt us to do something. The range of activities that can be monitored and prompted in a smart home is growing.**

A smart house might be programmed to:

- **Energise and motivate people to get up in the morning.**
- **Remind someone not to open the door to strangers.**
- **Monitor if someone has had breakfast.**

Contact us to share your views or learn more about our work in this area.
Email: research@brainkind.org

Further reading

Getting social care support

- The following link can provide useful information about how social care works and how to ask your local council for an assessment: **www.nhs.uk/conditions/social-care-and-support-guide/introduction-to-care-and-support/**

For carers

www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment

The Department of Health has created a set of factsheets about the Care Act: **www.gov.uk/government/publications/care-act-2014-part-1-factsheets**

Find local authority adult social care services in England here: **www.nhs.uk/service-search/other-services/Local-Authority-Adult-Social-Care/LocationSearch/1918**

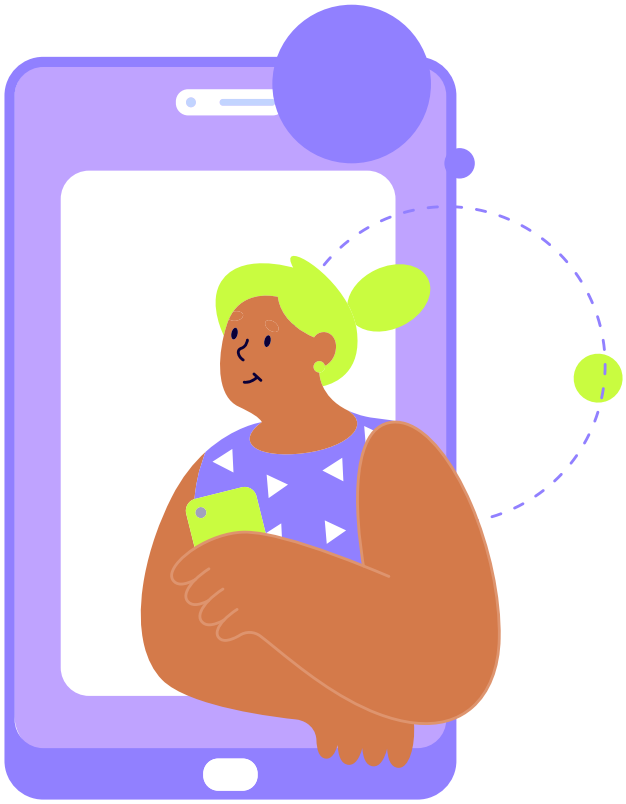
NHS social care and support guide: **www.nhs.uk/conditions/social-care-and-support-guide/**

Welsh government social care guide: **gov.wales/social-care**

About social care in Scotland: **www.gov.scot/Topics/Health**

Using technology in brain injury rehabilitation

Assistive Technology for Cognition, A handbook for clinicians and developers. Brian O'Neill and Alex Gillespie. (2015). Psychology Press.



This section explains how the Mental Capacity Act 2005 in England and Wales helps people with brain injuries to manage their money when they go into banks, building societies and post offices.

Section Ten:

Money and legal matters

Managing money

A brain injury can affect a person's ability to manage their financial affairs, temporarily or permanently.

It is important that people with brain injuries, and those caring for them, understand how the Mental Capacity Act can be used to protect their finances.

What is the Mental Capacity Act?

The Mental Capacity Act 2005 supports people in England and Wales to make their own decisions. It also gives legal protection if someone else needs to make a decision on behalf of a person who cannot make a decision for themselves.

"Mental capacity" means being able to make decisions by yourself. In Scotland, people with brain injuries are protected by the Adults with Incapacity Act 2000. If someone lacks capacity to make some or all decisions by themselves, the act safeguards their finances.

Why is the Mental Capacity Act important?

The Mental Capacity Act covers decisions when someone wants to take out money from an account or open an account at a bank, building society or Post Office. In this section, when we refer to bank or bank staff, we also mean building societies or Post Offices, including their staff.

The act recognises that someone's mental health and their ability to make decisions can change. For instance, a person with a brain injury may recover and be able to make important decisions again. So, capacity will need to be reviewed on a regular basis. You will need to be aware of this if you are providing care to a person with a brain injury over a period of time.

Sometimes people who have survived a brain injury find it difficult to open accounts and carry out transactions. Staff may think the person cannot manage their account even when they are able to. These difficulties may happen because of genuine misunderstandings, confusion or communication difficulties.

People with brain injuries should not be discriminated against as customers of banks, building societies or Post Offices. That is against the Disability Discrimination Act (1995).

Staff working in a bank, building society or Post Office will usually assume that a customer is able to make decisions about their money. Where necessary, bank staff should give clear and appropriate information to customers to help them make decisions about their money.

The Mental Capacity Act can help in these situations. On occasions, staff may believe that a customer does not have the mental capacity to make a decision about managing their money. For example, if the customer seems very confused, staff may be reluctant to serve them. In these situations, the Mental Capacity Act will apply and should be helpful to both staff and customers.

Mental Capacity Act principles

The Mental Capacity Act has five principles which must be applied when someone with a brain injury needs to make a decision. This includes situations where someone needs to make decisions about finances.

1. **Assume capacity**
Every adult is presumed to be able to make his or her own decisions, unless it is proven otherwise.

2. **Support**
People should be supported as much as possible to make their own decisions before anyone decides they cannot make a decision.

3. **Eccentric or unwise decisions**
A person has the right to make a decision that may seem unwise or strange to other people. The person should not be treated as lacking capacity.

4. **Best interests**
Anything done for, or decided on behalf of, a person who lacks capacity must be done in their best interests.

5. **Least restrictive option**
Anything done for, or on behalf of, a person without capacity should not restrict that person's basic rights and freedoms. But it must still be in their best interests.

Putting Mental Capacity Act principles into practice

If you are a customer making decisions about your money in a bank these principles mean things like:

- Bank staff should assume you have capacity to make your own decisions.
- You should have all the relevant information needed to make a decision. Bank staff can help with this.
- Bank staff should make sure the information is explained or given to you in a way you can understand. For example, they should consider any reading difficulties you may have, or hearing or speech difficulties.
- You can have someone you trust with you, such as a relative, friend or advocate, to help you understand information or make a decision.

When might the Mental Capacity Act apply in a bank, building society or Post Office?

If you are a customer, dealing with bank staff, you can use the act to:

- Open an account for the first time.
- Pay money into your account or someone else's account over the counter.
- Withdraw money over the counter.
- Discuss or apply for other services. For example, getting a loan.
- Talk about and arrange for someone else to have access to your account.
- Discuss any arrangements you have in place for someone to make decisions on your account because you do not have the mental capacity.

Finding out if someone has the mental capacity to make a particular decision

The Mental Capacity Act helps you to work out if you have mental capacity to make a particular decision.

If you have a brain injury, this may affect your ability to make decisions when you are in a crisis, distressed or confused. Mental capacity may also be affected by medication because it may make you feel drowsy or confused. If you are going into a bank to deal with your money, it is important you do this when you are feeling confident and well.

When making financial decisions, it is also important that you can understand and remember the information relevant to the decision, weigh up the information and communicate your decision. If problems with your brain injury are preventing you from doing this, you may not have capacity to make the decision. You could ask a friend, relative or advocate for support, or delay making the decision. Staff in a bank will assume you have capacity to make decisions. But if they have genuine concerns that you cannot make a decision, they may be reluctant to carry out the transaction you are asking for or suggest you delay it.

Staff must not decide that you lack capacity solely because of your age (as long as you are 16 or over), appearance, behaviour or disability, illness or injury. They must explain their reasons for not carrying out the transaction or for delaying it. If staff do carry out a transaction when you lack capacity to make decisions but they do not realise it, they may have to explain their reasons for doing this to their manager and, potentially, the courts.

The Mental Capacity Act Code of Practice gives more information about how to find out if someone has the mental capacity to make a particular decision.

What happens about decisions that need to be made involving money if I lack the capacity to make those decisions myself?

In some situations, for example if you are very unwell physically or mentally, you may be so distressed or confused that you lack the capacity to make some decisions yourself. It may be possible to delay making the decision until you feel better and can make it yourself.

Any decisions made on your behalf must follow two of the five principles of the Mental Capacity Act. They must be done in your best interests and be the option that least restricts your basic rights and freedoms.

What does acting in someone's "best interests" mean?

The Mental Capacity Act does not define "best interests". Instead, it explains what must be considered when deciding what is in the best interests of a person who lacks capacity. This includes:

- The person's past and present wishes and feelings, beliefs and values.
- Any written statements made by the person.
- A friend, relative or advocate who has been named by the person lacking capacity as someone who should be consulted.
- The views of others who have an interest in the person's welfare, such as close relatives, friends, or staff providing support to the person.
- The views of the person who lacks mental capacity if they can communicate them, even if they cannot make the decision.
- The Act contains strict safeguards to make sure a person's money is protected if they lack mental capacity. The Act does not allow anyone to make decisions involving money in the person's best interests, unless they have legal powers to do so.
- The Mental Capacity Act Code of Practice gives more information about what the law says about best interests.

What legal powers allow other people to make decisions about my money, on my behalf, if I lack capacity to make these decisions?

Under the Mental Capacity Act, only people who have one of the following legal powers are able to make decisions on your behalf:

- **A Lasting Power of Attorney (LPA)**
  This allows you to appoint a close relative to make certain decisions, including financial ones, on your behalf. You can choose whether you want the attorney to make decisions when you still have capacity or only when you do not have capacity.
- **An Enduring Power of Attorney (EPA)**
  These are similar to LPAs but the EPA must have been appointed before October 2007. After this date, LPAs have to be used instead.
- **A General Power of Attorney (GPA)**
  Also known as an Ordinary Power of Attorney. This is a legal document which is drawn up when a person has the capacity to understand they are giving someone else the power to manage their affairs and what this means in practice.
- **A Court Appointed Deputy**
  This is someone who has been given the power by the Court of Protection to make financial decisions on someone's behalf if they lack capacity.
- **Appointeeship**
  An individual, for example a friend or relative or the representative of an organisation, like a solicitor or local council, can be nominated as an appointee of the Department for Work and Pensions (DWP). They will manage a person's welfare benefit payments when they do not have the capacity to do it themselves.

These legal powers can be complex
If you lack capacity to make a decision, they make sure there are safeguards in place to protect you.

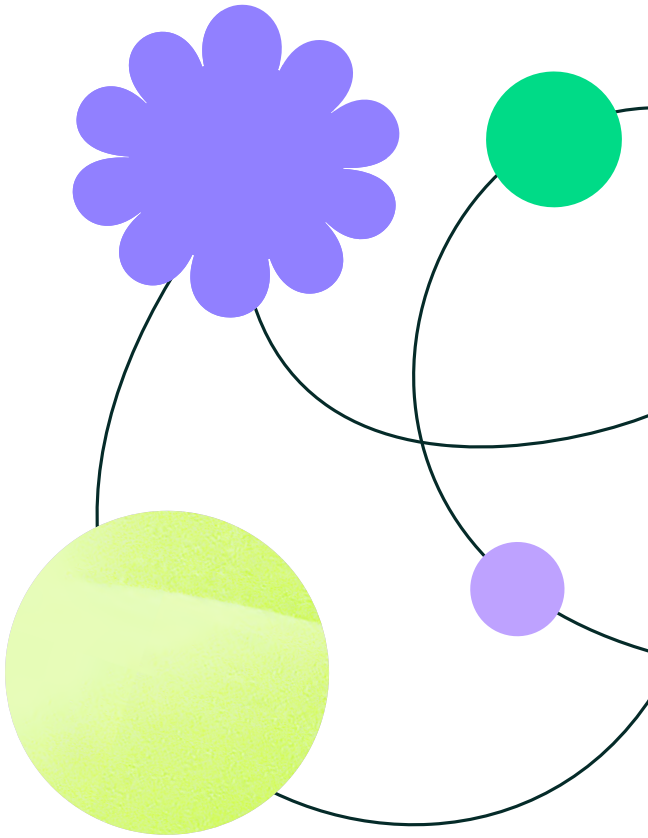
When can Lasting Power of Attorney (LPA), Enduring Power of Attorney (EPA) and General Power of Attorney (GPA) be used?

LPA, EPA and GPA could be used at any time after they have been appointed by the court. That is unless the person with a brain injury has said they must not be used while they have the capacity to manage their own finances.

Some people want their attorneys to take over the management of their finances even though they can still manage them themselves. For instance, they may want their attorney to manage their bank accounts and deal with bills because they do not like dealing with money. Others may only want their LPA to be used when they lack capacity to make decisions for themselves.

Unless the person has placed any restrictions on the registration document for the role of attorney, the GPA will be able to sign cheques, operate bank accounts, make investments and buy and sell property in the person's best interests. The GPA will have to keep the person's money separate from their own and produce detailed accounts should they be asked to do so by the Office of the Public Guardian. The GPA cannot make any decisions about health and welfare unless they have also been appointed as a Personal Welfare Attorney.

Someone could also be an appointee of the Department for Work and Pensions (DWP), so they have the power to manage a person's welfare benefit payments. This is when the person with a brain injury does not have the capacity to do this themselves. Appointees are covered by different laws but must follow the Mental Capacity Act principles. Please see the section of this guide about Mental Capacity Act principles for more details.



What happens if bank staff are reluctant to serve me when I have an LPA but I still have capacity. Or when they are reluctant to serve my attorney?

Banks may find it confusing if you have an LPA which may or may not be used depending on whether you have mental capacity. You may want to discuss with your bank what arrangements could be made to prevent any confusion.

If the bank staff are reluctant to serve you, it is important to stay calm because neither you nor your attorney can force them to carry out a transaction.

Ask to speak to the manager. If you and your attorney are familiar with the Mental Capacity Act, you can tell the manager and staff why you believe you or your attorney should be served. If staff are still reluctant to serve you, then you can ask to make an official complaint. For more on this, please see the section of this guide called What can I do if I have concerns or want to make a complaint?

Are there other ways I can give permission to someone else to have access to my money when I have mental capacity?

Sometimes you may want to give permission to someone else to access your money or account. This may be because it is convenient, or because you are housebound or going away. This can be done with direct debits and joint accounts.

You can also use a third-party mandate to instruct your bank or building society to allow someone to access your account. To find out more about this, and other options for letting other people access your account or handle your financial affairs, you can ask your bank or contact one of the organisations listed in the **Useful contacts** box at the end of this section.

Are there other laws about opening accounts?

It is important to remember there are laws which banks, building societies and Post Offices follow which are nothing to do with mental capacity. These are about proving you are the person you say you are to stop fraud and money laundering.

Different banks may ask for different types of identification including photographic ID (for example a passport) and documents with proof of your address (for example, a water, gas or electricity bill).

What can family members do and not do?

Family members often find themselves in a difficult financial position when someone has a brain injury. If you have joint accounts, then you can carry on using these as you always have. If you do not have joint accounts, then you will not be able to access the person's accounts. If standing orders and direct debits have been set up, these should continue to be paid as long as there are sufficient funds in the accounts.

If there are no arrangements in place, the situation can be difficult. Lasting Power of Attorney may be possible if a person with a brain injury has the capacity to understand what this role means and give their approval. If not, you may need to go through the Court of Protection, which can be expensive. The Court of Protection makes decisions about financial matters for people who cannot make decisions at the time they need to be made.

Even with joint accounts or assets, the family member must act in the best interests of the person with the brain injury. For example, jointly owned property should not be sold unless it is in the interests of the injured person.

If the property is sold, the person with a brain injury is entitled to half of the proceeds.

What can I do if I have concerns or want to make a complaint?

If you have concerns or want to make a complaint about the service you have received from a bank, building society or Post Office you can ask the staff how you go about doing this. If this does not work, you can take your case to the Financial Ombudsman Service.

If you have concerns, or want more information about the Mental Capacity Act, you should contact the Office of the Public Guardian. This is a government body that is responsible for making sure deputies, attorneys and guardians carry out their duties appropriately.

Useful contacts

- UK Finance
  www.ukfinance.org.uk
- Financial Ombudsman Service
  www.financial-ombudsman.org.uk
- Office of the Public Guardian
  www.publicguardian.gov.uk

“I’ve been super lucky, knowing how damaging a stroke can be.”

“I have got no problems apart from not being able to work still. So, I’ve been super lucky. Both with the benefits in this country, and the healthcare system and everything.”

Ian, 46, who had a brain injury in 2021.

Getting legal advice and accessing welfare benefits

Dealing with a brain injury can be challenging. As well as managing day-to-day life with a brain injury, you may need to get support with personal injury claims and welfare benefits. Legal specialist Irwin Mitchell answers some of your common questions.

This section of the guide provides guidance about making a personal injury claim and claiming welfare benefits in England and Wales.

You should get further advice if you live in Scotland. Contact Citizen’s Advice Scotland or visit the Scottish government website.

Frequently asked questions

Q. I think I have a personal injury claim for the brain injury I have sustained. How do I find the right solicitor for me?

A. Brain injuries are complex and may have a life-changing and long-term impact on someone's life and those around them. So, it is important to find the right solicitor to work on your case. You need to be satisfied that any potential solicitor has experience of successfully representing people with brain injuries.

Look for a solicitor with accreditation from the Association of Personal Injury Lawyers (APIL) in particular someone with Specialist Brain Injury Accreditation or Senior Litigator / Fellow status.

You should also look for those who have specialist Law Society Personal Injury Practitioner status which requires someone to demonstrate a certain level of experience.

Q. When can I make a claim?

A. Claims usually need to be made within three years of an accident. There are exceptions to this. For people who sustained their injury in childhood, the three-year time limit does not start running until their 18th birthday. In cases involving people with very severe brain injuries, a court can decide that the normal time limits will not apply as the person may not have the capacity to partake in legal proceedings.

This type of exception should never be relied on without getting specialist legal advice. Where a brain injury is caused by criminal assault, the time limit for making a claim may also be different. It is usually two years from the date of the injury or assault. It is also important to note that different types of accident, and accidents in different jurisdictions outside England and Wales, may also have different time limits. You should seek specialist legal advice at the earliest possible opportunity.

Q. Do I have a case?

A. A civil case is a legal case which involves disputes between individuals or organisations in which some form of compensation may be awarded. To succeed in a civil case, you have to show that:

1. The defendant, a person or organisation, has a legal duty of care to protect you. For example, a common law duty (negligence) or a statutory duty (such as those imposed by the Road Traffic Act or legislation relating to the workplace).

2. The defendant has breached their duty of care by doing something wrong. Sometimes this is obvious, such as in some car accidents, but other times it can be more complex.

3. The defendant's fault caused or materially contributed to the accident and injuries and losses.

The above requirements apply to:

- **Road traffic collisions**
- **Accidents at work**
- **Accidents in a public place**
- **Cases where clinical negligence has occurred, such as not being given the level of appropriate care expected of a medical professional.**

Sometimes medical experts will be asked to help consider these issues as part of a personal injury claim.

Cases that fall under the Criminal Injuries Compensation Authority (CICA), where someone has been physically or mentally injured because they were the innocent victim of a violent crime in England, Scotland or Wales, have strict eligibility criteria. It is possible to succeed in a CICA case even if the person who carried out the attack, was not convicted of a criminal offence. We strongly recommend you speak to an experienced solicitor for advice as early as possible.

Q. Do I have to know who the "defendant" is?

A. The Defendant is the opponent in the claim. Usually, you and your solicitor have to identify who was at fault and be comfortable that they have the financial resources (such as insurance or other means) to pay the compensation awarded and cover legal costs.

There are some limited circumstances where you may be able to secure compensation even if you do not know who was at fault. For example, in cases where drivers leave the scene of a road traffic accident (known as untraced cases) or the driver was uninsured. There are special rules that apply to these types of cases and you will need to get specialist legal advice.

Similarly, if you have been the victim of fraud, you may not be able to identify who the assailant was. But you may still be able to recover compensation if you can meet the necessary eligibility criteria.

Q. How is my case funded?

A. Find a firm of solicitors that offers free initial legal advice on cases and provides information on how to cover the cost of taking legal action so you know what the options are for you. Alternative methods of funding a case include:

- **Conditional fee agreement**

Commonly known as a “no win / no fee” agreement, these usually have no up-front costs. But you are likely to may be responsible for some costs at the end of the claim if your case is successful. Some, but not all, of these costs are capped by law.

- **Legal expenses insurance**

Also known as “Before the Event Insurance”, it is often sold as part of car and household contents insurance policies, but all insurance policies should be checked and also your bank and any credit card terms. This type of insurance covers legal fees up to a certain financial limit (known as the limit of indemnity).

- **Trade union funding**

If you or a family member are part of a union, trade union funding may be available, although you are likely to be restricted in your choice of legal representative.

You should not usually be asked for any payments up front and your solicitor should explain the different funding options to you, together with the likely costs you may have to pay if your claim is successful.

Your solicitor should also make sure you are protected from any costs in the event your claim is unsuccessful. You should receive detailed estimates of costs throughout the claim. You are entitled to have your costs independently assessed by the court at the end of the claim. This is mandatory for anyone who lacks capacity or is a child.

Q. What is the procedure for making a claim?

A. Your solicitor should identify the defendant and, where appropriate, their insurer as soon as possible, and notify them of your potential claim. All personal injury claims must follow the Personal Injury Pre-Action Protocol, which imposes certain obligations and timeframes on the people involved. For example, responding within set time frames and considering rehabilitation at the earliest possible stage and throughout the claim.

Q. How will my rehabilitation be funded?

A. Your solicitor should let you know about other ways to fund your rehabilitation, if your claim is not successful:

- **The rehabilitation code (The Code)**

The Code encourages both sides to look at someone’s rehabilitative needs at the earliest possible opportunity and arrange for an appropriate clinician to undertake an “Initial Needs Assessment”. Any recommendations that are made

should be carried out and paid for by the defendant or their insurers irrespective of what happens in the claim.

- **Interim payments**

Your solicitor can advise whether your rehabilitation could be covered by interim payments (money paid on account of the claim whilst the claim is still ongoing) made by the defendant. If successful, these payments can be used to address your needs at an early stage. These costs can be recovered as financial loss in your compensation claim.

- **Private health policies**

Your solicitor should investigate what is available under any private health policies you have, which may assist you in accessing rehabilitation and treatment. Those costs sometimes have to be repaid but can be claimed within your claim.

- **Statutory provision** You may be entitled to rehabilitation and treatment under the NHS or your local authority. If you believe they should be providing this but they are not, your solicitor can help you challenge the services to ensure you can access services you are entitled to.

Q. How can I cover my immediate financial needs and ongoing costs while my case is being progressed?

A. You may be able to access:

- **State benefits (see below)**
- **Interim payments from the defendant**
- **The rehabilitation code payments**
- **Insurance payments paid through your car, home, credit card or other insurance policy. This is usually paid in a lump sum.**
- **Insurance payments that you may be entitled to through permanent health or critical insurance policies. This is also known as income protection insurance.**

Q. What benefits can I expect to get because I have got a brain injury and where can I find advice?

A. There are three types of benefits:

1. **Income replacement or top up.** This includes Statutory Sick Pay (SSP), Universal Credit (UC), and Employment Support Allowance (ESA). These are benefits for people who cannot work because of an illness or disability or if they have a low income which can be topped up by Universal Credit.

2. **Disability payments.** Disability Living Allowance (DLA), Personal Independence Payments (PIP) or Attendance Allowance (AA) are given to people with a disability or those with a long-term illness. Which one you get and how much you receive, will depend on your age and personal circumstances.

3. **Passported benefits.** These are benefits that some groups of people can claim because they are entitled to other benefits, like those mentioned above. These include a Blue Badge (a parking permit for disabled people), reduction or exemption on council tax, reduction in some utility bills and free prescriptions.

You can get further advice from your local Citizens Advice Bureau (www.citizensadvice.org.uk/) or through the Turn2Us website: www.turn2us.org.uk.

You can also get advice from your local authority's welfare benefits advice services. Phone your local authority and ask to speak to this department. If your local authority does not have this service, you can visit Advicelocal to find out where else to get support with accessing benefits: https://advicelocal.uk/

Q. What happens if I cannot manage my own legal action?

A. If your brain injury affects your ability to manage your own case, a "litigation friend" will be appointed to act on your behalf and give your solicitor instructions. A litigation friend is someone who helps an adult who cannot manage their own legal affairs. A friend or family member can apply to be a litigation friend, or the courts can appoint someone. Any settlement reached on behalf of someone who cannot manage their own case has to be approved by the court to protect them.

A litigation friend is also needed for anyone bringing a claim who is under the age of 18.

Q. What happens if I cannot manage my own finances?

A. A financial deputy can be appointed to manage the finances of someone whose brain injury prevents them from doing this. This can be either a professional deputy (someone who is paid) or a lay deputy (someone who is not paid). It is possible to recover the costs of a professional deputy as a loss in the compensation claim.

Q. Will I have to see medical experts?

A. To support your claim, your solicitor will ask medical and non-medical (for example, care and accommodation) experts to examine you. This will help to determine what rehabilitation you need and how much this will cost. Usually, you will be examined by experts who have been instructed for the defendants too.

Q. How much compensation will I receive and how is it calculated?

A. There are two types of compensation:

1. General damages are awarded for non-financial loss, such as the pain and suffering someone has experienced, and how their quality of life has been affected by the injury.

Factors such as someone's age, life expectancy, occupation and extent of injury are used to determine the value of the claim. These are tariff based awards determined by the Judicial College Guidelines.

2. Special damages are awarded for the financial loss you have already had and what you will incur in the future. This includes loss of earnings and pension, care and assistance, including professional case management, accommodation and transportation needs caused by the injury, aids and equipment, medical treatment costs, costs of a deputy and any other financial costs arising from the injuries.

Q. Will I get all of my compensation at the end of the claim?

A. At the end of a case, compensation is typically awarded as a one-off-lump sum payment. But it is also possible to be awarded compensation on an annual basis to cover future losses. For example, future care and managing someone's health needs. These are known as periodical payments (PPOs) Here is some more information about these two types of payments:

Lump sum

The pros:

- You have closure on what has happened as no further contact with the defendants or their insurers is needed.
- You have the freedom to do whatever you want with the full lump sum.
- If the person with a brain injury dies, the remainder of the compensation goes into their estate, potentially benefiting their family.

The cons:

- You are expected to invest your compensation. This sometimes exposes you to risky investments and the value could go down as well as up.
- If you live longer than anticipated, the funds could run out before your death.

Periodical payments

The pros:

- These payments are tax free and index-linked which means they are guaranteed annually for life. They also increase over time in line with inflation relevant to the type of payment to avoid underpayment.
- The need for investment and the associated risk that comes with this is therefore taken away.

The cons:

- There is less flexibility as you do not have all your compensation up front.
- The periodical payments end when you die. If you die earlier than anticipated, your family will not benefit from this money.

You should speak to an independent financial adviser to get advice about the pros and cons of each type of settlement. A financial adviser can also talk to you about investing and managing a substantial settlement. Where someone lacks financial capacity, the financial deputy will seek financial advice on their behalf. It is important to choose a financial adviser who has specialist expertise in protecting and investing personal injury settlements.

Q. Will my case go to trial?

A. Most cases settle before they go to trial, but it is important to prepare in case it does go to trial. There are many opportunities to settle a case, such as either side making an offer, or both parties taking part in alternative dispute resolution. This includes joint settlement meetings or mediation.

Q. Can I change my solicitor?

A. If you have concerns about how your case is being managed, you can usually get a free second opinion from another solicitor. You have a right to choose your own legal representative and change your solicitor at any time. It is important to consider a second opinion if you have concerns about any aspect of your case, such as delays, poor communication, a lack of interim payments, little or no rehabilitation or worries about whether your lawyer is a specialist in personal injury.

Getting legal support

Getting support following a brain injury is about more than just compensation. A brain injury can affect all aspects of your life as well as your family's. That is why a legal team will support you and your family to get the best possible medical care and rehabilitation. To see how Irwin Mitchell can help you, get in touch on:

Freephone: **08000 23 22 33**

For a list of our offices visit our website: www.irwinmitchell.com.

Irwin Mitchell LLP is authorised and regulated by the Solicitors Regulation Authority.

The Brain Injury Group is a network of specialist solicitors and other professional services providing support for people with brain injury and their families.

Free helpline:
0800 612 9660 or 0330 311 2541

www.braininjurygroup.co.uk

Goodbye, from Emma

Emma Rich, who welcomed you to this guide, shares more of her recent story and discusses what helped her heal.

I hope that you have found the information in this guide helpful – and hopeful.

If I could give some advice to myself when I woke up in hospital after having a brain injury, I would say to always remember there is hope.

In the past, many doctors believed that two years of improvements were all a person could expect to gain after a brain injury. But recent research is beginning to challenge that idea and we now know that you still activate neuroplasticity years – and even decades – after a brain injury.

The speech, art and music therapy that I did during my rehabilitation through Brainkind was so important for me. The activities bring back your confidence. I learnt to walk again and the friendships I made at rehab all interlinked with improving skills.

Now, I'm home with my family, getting back to normal. I've signed up for art and sign language classes and am enjoying gardening. I'm also doing some befriending with a 90-year-old lady called Kitty. I'm planning to go back to work as a HR director, doing a job share.

Every day is different. Some days I have bad days or more pain than others. I have learned that knowing when you've had enough, and you just need to go to bed, is important.

Looking after yourself

My advice is to take each day as it comes. There's not a finite time for recovery. Your brain can take a while to heal. But you know what? It can improve at any stage.

I'm so grateful for all the help I have received from various people, including my family and friends and the staff and community team at Brighton Hospital, especially Kirsty. And a very special thanks to the team at Brainkind's Kerwin Court for all their help in my rehabilitation.

I couldn't have got this far without your professionalism, dedication, and care.

Good rehabilitation is so important and, in most cases, the NHS can refer you to services.

To live with a brain injury, you have to look after yourself and take advice from where you can. You don't have to do everything by yourself.

Take a look at the Further reading section of this guide and the Directory of useful contacts to find out what help is out there and who you can contact next.

Emma Rich

Directory of useful contacts

Access to Work
Website: www.gov.uk/access-to-work
Tag: Benefits advice

Activity Alliance
Website: www.activityalliance.org.uk/
Phone: 01509 227750
Email: Contact form:
www.activityalliance.org.uk/contact-us
Tag: Leisure, sport, activity

Advicelocal
Website: https://advicelocal.uk/
Email: Contact form:
https://advicelocal.uk/contact
Tag: Benefits advice

Alcoholics Anonymous
Website: www.alcoholics-anonymous.org.uk
Phone: 0800 9177 650
Email: help@aamail.org
Tag: Alcohol and drugs advice

Autopage (electronic paging system)
Website: www.autopagesolutions.co.uk/
case-study-neuropage.php
Phone: 01603 506441
Email: sales2021@autopagesolutions.co.uk
Tag: General information and support,
reminder technology

Brain Injury is Big
Website: www.braininjuryisbig.org.uk
Phone: 01483 770999
Email: info@braininjuryisbig.org.uk
Tag: General information and support

British Association for Supported
Employment (BASE)
Website: base-uk.org
Phone: 01252 912829
Email: admin@base-uk.org
Tag: Employment advice

Care Information Scotland
Website: www.careinfoscotland.scot
Phone: 0800 011 3200
Tag: General information and support

Carer support groups
www.braininjuryisbig.org.uk
www.headway.org.uk/about-brain-injury/indi-
viduals/caring/carer-support-groups/
Tag: Local support

Charity Job
Website: www.charityjob.co.uk/
Volunteer-Jobs
Phone: 020 8939 8430
Email: info@charityjob.co.uk
Tag: Employment advice, volunteering,
job opportunities

Citizens Advice
Website: www.citizensadvice.org.uk
Phone: 0800 144 8848 (England);
0800 702 2020 (Wales);
0800 028 1456 (Scotland)
Tag: General information and support,
benefits, debt

Disability Jobsite
Website: www.disabilityjobsite.co.uk
Tag: Job opportunities

Disability Sport Wales Website:
disabilitysportwales.com
Phone: 0300 300 3115
Email: office@disabilitysportwales.com
Tag: Leisure, sport and activity

Do IT
Website: doit.life/about
Email: hello@doit.life
Tag: Volunteering

DVLA Medical Inquiries
Website: www.gov.uk/contact-the-dvla/y/driving-and-medical-issues
Phone: 0300 790 6806
Email: Contact form: contact.dvla.gov.uk/email
Tag: General information and support, driving

Fair Start Scotland
Website: www.remploy.co.uk
Phone: 0300 456 8110
Email: Contact form: www.maximusuk.co.uk/contact-us
Tag: Employment advice, learning, training

Financial Ombudsman
Website: www.financial-ombudsman.org.uk/contact-us
Tag: Making complaints, legal matters

Headway
Website: www.headway.org.uk
Phone: 0808 800 2244
Email: helpline@headway.org.uk
Tag: Information and support for people with brain injury, Brain injury ID card

Intensive Personalised Employment Support
Website: www.gov.uk/intensive-personalised-employment-support
Tag: Employment advice

Irwin Mitchell (legal support)
Website: www.irwinmitchell.com
Phone: 08000 23 22 33
Tag: General information and support, legal advice

Jobcentre Plus
Website: www.jobcentreguide.co.uk/jobcentre-plus-guide/34/about-disability-employment-advisors
Email: Contact form: www.jobcentreguide.co.uk/about-us/5/about-the-jobcentre-guide
Tag: Benefits, employment advice

Leonard Cheshire
Website: www.leonardcheshire.org/get-support/learning/can-do
Phone: 020 3242 0200
Email: Contact form: www.leonardcheshire.org/about-us/contact-us
Tag: Volunteering, learning, training

Mental Capacity Act Code of Practice
Website: www.gov.uk/government/publications/mental-capacity-act-code-of-practice
Tag: Mental health and mental capacity

Mind
Website: www.mind.org.uk
Phone: 0300 123 3393
Email: info@mind.org.uk
Tag: Wellbeing and mental health

MSKTC
Website: msktc.org/tbi
Phone: (001) 202-403-5600 (USA)
Email: msktc@air.org
Tag: Science-based information about living with a brain injury

My Therappy
Website: www.my-therappy.co.uk
Phone: 01271 314123
Email: ndht.mytherappy@nhs.net
Tag: Apps and technology, living with a brain injury

National Careers Service
Website: nationalcareers.service.gov.uk
Phone: 0800 100 900
Tag: Employment advice

NCFE
Website: www.ncfe.org.uk/about-ncfe
Phone: 0191 239 8000
Email: customersupport@ncfe.org.uk
Tag: Training, learning

NCVO (England)
Website: www.ncvo.org.uk
Phone: 020 7520 2414
Email: membership@ncvo.org.uk
Tag: Volunteering

NHS (Insomnia self-assessment)
Website: www.nhs.uk/conditions/insomnia
Tag: Sleep support, wellbeing and mental health

NHS Live Well
Website: www.nhs.uk/livewell
Tag: Wellbeing, alcohol and drugs advice

Office of the Public Guardian
Website: www.gov.uk/government/organisations/office-of-the-public-guardian
Tag: Making complaints, legal matters

Outsiders
Website: www.outsiders.org.uk
Phone: 07872 681 982
Email: members@outsiders.org.uk
Tag: Dating, relationships

PALS (Patient Advice and Liaison Service)
Website: www.nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service/
Tag: Making complaints, benefits advice, general information and support

Peer support groups for people living with a brain injury
www.headway.org.uk/supporting-you/in-your-area/
www.braininjurygroup.co.uk/brain-injury-group-directory/charities-support-groups/
www.sayaphasia.org/Pages/Category/drop-in-groups
Tag: Local support

Reach Volunteering
Website: reachvolunteering.org.uk
Phone: 0203 925 7721
Email: info@reachvolunteering.org.uk
Tag: Volunteering

Remploy
Website: www.maximusuk.co.uk/our-services/employability
Phone: 0300 456 8110
Email: Contact form: www.maximusuk.co.uk/contact-us
Tag: Employment advice, learning, training

Rethink
Website: www.rethink.org
Phone: 0808 801 0525
Email: Contact form: www.rethink.org/aboutus/what-we-do/advice-and-information-service/contact-our-advice-information-service/
Tag: Wellbeing and mental health

Samaritans
Website: www.samaritans.org
Phone: 116 123
Email: jo@samaritans.org
Tag: Wellbeing and mental health

Say Aphasia
Website: www.sayaphasia.org
Phone: 07796143118
Email: colin@sayaphasia.org
Tag: Local support, communication support

Scottish Disability Sport
Website: www.scottishdisabilitysport.com
Email: admin@scottishdisabilitysport.com
Tag: Leisure, sport and activity

Sleep Foundation
Website: www.sleepfoundation.org
Email: contact@sleepfoundation.org
Tag: Sleep support

Sport England
Website: www.sportengland.org/our-work/disability/
Email: Contact form: www.sportengland.org/contact-us
Tag: Leisure, sport and activity

Stroke Association
Website: www.stroke.org.uk
Phone: 0303 3033 100
Email: helpline@stroke.org.uk
Tag: Living after a stroke, general information and support

Talk To Frank
Website: www.talktofrank.com
Phone: 0300 1236600
Email: Contact form: www.talktofrank.com/contact
Tag: Alcohol and drugs advice

Brainkind
Website: www.brainkind.org
Phone: 01444 239123
Email: info@brainkind.org
Tag: General information and support, specialist neurological and brain injury rehabilitation services

The Shaw Trust
Website: www.shaw-trust.org.uk
Phone: 0300 30 33 111
Email: support@shaw-trust.org.uk
Tag: Employment advice, job opportunities

The Work and Health Programme
Website: www.gov.uk/work-health-programme
Tag: Employment advice, job opportunities

U3A
Website: www.u3a.org.uk
Phone: 020 8466 6139
Email: info@u3a.org.uk
Tag: Learning, training

Volunteer Now (Northern Ireland)
Website: www.volunteernow.co.uk
Phone: info@volunteernow.co.uk
Email: 028 9023 2020
Tag: Volunteering

Volunteer Scotland

Website: www.volunteerscotland.net

Phone: 01786 479593

Email: hello@volunteerscotland.org.uk

Tag: Volunteering

Volunteering Matters

Website: volunteeringmatters.org.uk

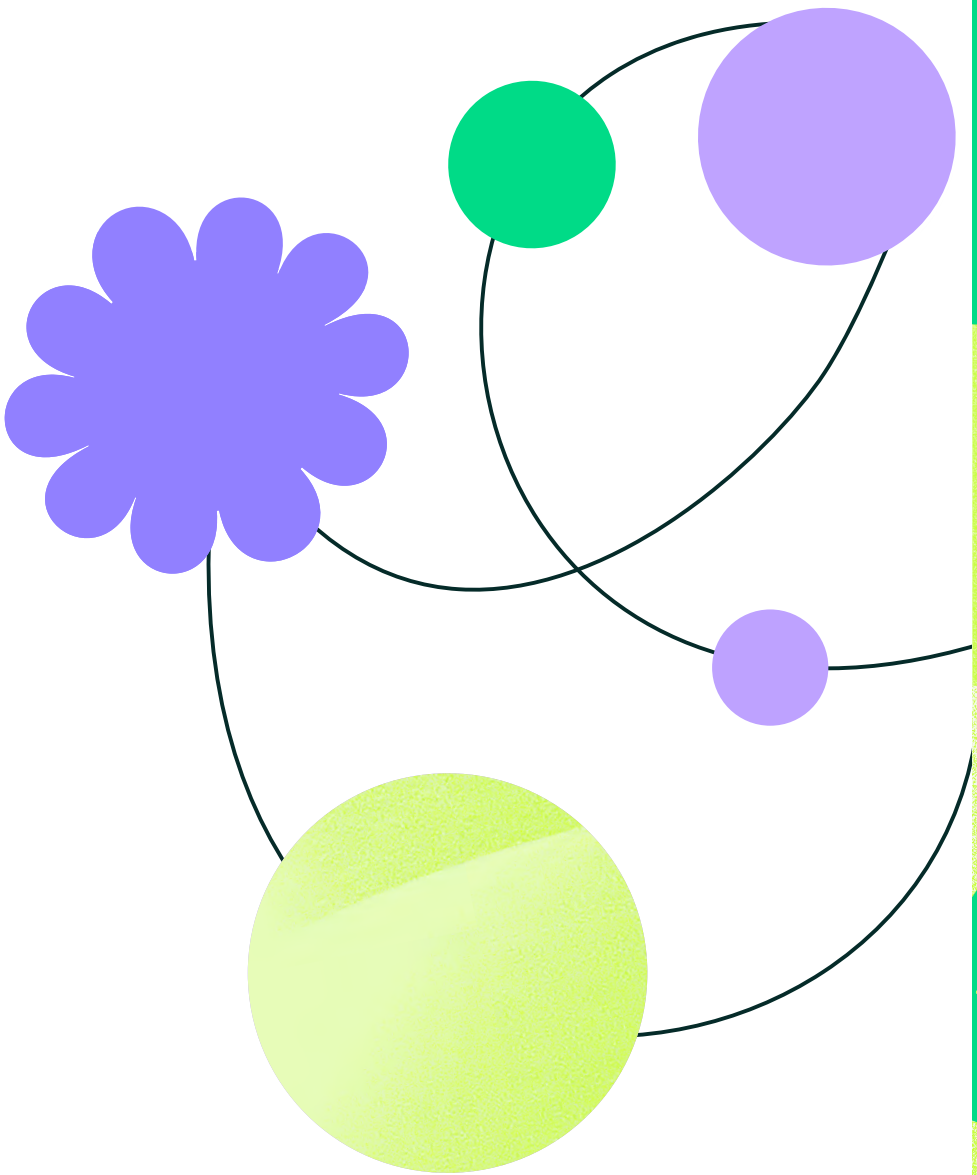
Tag: Volunteering

Volunteering Wales

Website: www.volunteering-wales.net

Email: volunteering@wcva.cymru

Tag: Volunteering



Thank you

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“One day, I decided to push myself even further. I walked to a nearby shop with a staff member. That was about half a mile. I no longer need a wheelchair. I never gave up.”

“My dreams and hopes for the future are to live independently with my son and a dog. I would say to people ‘never to give up’ as my determination has got me to where I am.”

Hannah, 33,
who lives in Blackpool

Find out more

Do get in touch for more information about how we can help you or a loved one, to refer someone to our services or to offer feedback on this guide.

Phone: 0330 0581 881

Referrals email: brainkind.referrals@nhs.net

Address: Brainkind, 32 Market Place,
Burgess Hill, West Sussex, RH15 9NP

Brainkind

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