Anxiety after brain injury



This publication is part of Headway's *Effects of brain injury* series. To browse through our publications on a range of issues relating to brain injury and download these free-of-charge, visit www.headway.org.uk/information-library.

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Introduction

After having a brain injury, people can experience a wide range of emotions, including anxiety. Anxiety is a common consequence of brain injury, and there are many reasons why someone may feel anxious after their injury. There are a range of symptoms associated with anxiety, from mild to severe, and it can interfere with various aspects of life such as relationships, employment and emotional well-being.

This publication describes what anxiety is, symptoms associated with anxiety, why it can develop after brain injury, how to get professional support and things you can try at home to help you cope.

The information in this publication does not replace clinical guidance from medical professionals. You should always seek advice from a GP or other suitably qualified professional for help with managing the effects of brain injury.

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What is anxiety?

Anxiety can be described as a feeling of worry, fear (being 'on edge') or tension felt in response to stressful or 'threatening' life events. It is a normal and natural response to many situations, and often improves once the stress or 'threat' has passed.

Some people can feel this heightened sense of worry or fear on a regular, or even constant basis, even if there is no particular cause of stress or obvious threat. These feelings can cause the person significant distress, and interfere with their daily life.

Some common symptoms of anxiety include:

- Regular or constantly feeling 'on edge', nervous, restless, worried or fearful
- Dizziness or feeling faint (outside of another medical condition)
- Fast or irregular heartbeat (palpitations, outside of another medical condition)
- Feeling sick (outside of another medical condition)
- Finding it difficult to go to or stay asleep
- 'Racing thoughts'
- Constant 'what if' questions and a sense or feeling of uncertainty

Thoughts of self-harm and suicide

For some people, feelings of anxiety may lead to thoughts about harming themselves or suicide. These thoughts can be distressing and difficult to manage.

It can be helpful to have a plan for what to do when these thoughts occur (e.g. call a friend/ family member, have a planned activity that you enjoy, contact agencies that can support you). Help is available, and you do not have to manage these thoughts and feelings alone. Even if you do not think that you will act on your thoughts, it is still helpful to talk with your GP or other medical professional about how you are feeling so that the right support can be provided.

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You can also text SHOUT to 85258, call the Samaritans on 116 123 or contact your local NHS urgent mental health helpline for help. The StayAlive app provides a resource with lots of useful information on how to stay safe in a crisis.

The Headway helpline is also available to offer emotional support and advice on any aspect of life after brain injury, including feelings of anxiety. We are available on 0808 800 2244 or helpline@headway.org.uk.

If you feel the need to self-harm or have already harmed yourself and need immediate help, call 999 or visit your local A&E department.

How can a brain injury cause anxiety?

Anxiety after brain injury can be caused by:

- organic damage to parts of the brain that are responsible for emotional or hormonal regulation;
- concerns over recovery from brain injury and uncertainty of/fears for the future;
- living with the effects of brain injury;
- changes in relationships, employment status, income;
- circumstances surrounding the injury itself, for example being treated in hospital or having been involved in an accident.

Below we will cover each of these causes in further detail. Remember though, that one in four people in the general population experience anxiety at any one time, and there are other, numerous, personal circumstances that can cause anxiety outside of brain injury.

Organic damage or hormonal imbalances

Damage to parts of the brain responsible for emotional and/or hormonal

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regulation may be responsible for causing the brain injury survivor to feel anxious.

Parts of the brain responsible for regulating emotions include areas called the amygdala, hippocampus and cingulate gyrus, which together make up a structure called the limbic system. Damage to the limbic system can cause problems with regulating emotions, which can result in feelings of anxiety.

Other parts of the brain called the pituitary gland and the hypothalamus are involved in hormonal regulation. Damage to these areas can affect the production and release or hormones called cortisol and adrenaline, which can cause feelings of anxiety.

A brain injury is like a fingerprint, no two are the same. With this in mind, it is important to seek professional support to better understand how organic damage or hormonal imbalances may or may not be contributing to your feelings of anxiety.

A good example of this might be damage to a part of the brain called the hippocampus, which is responsible for new learning - damage to this area affects memory, and so people might feel more anxious because they are forgetting more things.

Speaking to a professional such as a neuropsychologist about developing something called a 'biopsychosocial formulation' would be helpful here. A biopsychosocial formulation is a way of making sense of your symptoms by considering biological, social and psychological factors that contribute to a particular experience.

A neuropsychiatrist is another specialist who can treat anxiety (and other emotional changes and symptoms). A neuropsychiatrist can prescribe medications that evidence shows are helpful after brain injury. This might help especially if the 'biological' impact of brain injury has been shown to be a key factor in how a survivor's symptoms are being triggered.

Neuropsychologists and neuropsychiatrists often work alongside each other to develop a targeted treatment plan to help with anxiety where needed.

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Concerns over recovery

For many people with brain injury, and their families, there are concerns over recovery and fears for the future. While these are perfectly normal and valid feelings, especially in the early days of injury, such worries can be a cause of anxiety for some brain injury survivors and their families.

People may be especially anxious about whether they will return to their 'normal', pre-injury self, or return to important aspects of their life such as working or driving.

There may be anxiety around access to specialist support such as rehabilitation, which, unfortunately, can take some time to access due to long waiting lists. Our publication *Waiting for rehabilitation after brain injury* might help in these instances.

A brain injury can be life-changing, and it is often not possible to predict how the future will look. However, with the right support, advice and resources, many people go onto developing fulfilling lives even after their brain injury - see our website <u>Brain injury and me</u> for inspiring stories from real brain injury survivors on living life after brain injury.

For many people, finding certainty in the uncertainty can be helpful. This may include getting extra support from family and friends, getting involved in hobbies or sometimes just talking about how uncertainty feels.

Living with the effects of brain injury

There are many different effects of brain injury, and these can often be difficult to adjust to. The effects of brain injury can be physical, cognitive, behavioural and emotional, all of which can have an impact on various aspects of life such as daily living skills, relationships and employment.

Here are just some examples of how the effects of brain injury can cause anxiety:

Sensory overload - some survivors find it difficult to be in busy environments
where there are crowds of people, bright lights or lots of noise. Being in such
an environment can cause anxiety for some survivors due to overstimulation.

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- Memory forgetting key events such as birthdays or anniversaries, or being unable to remember people the survivor has already met, can be a cause of anxiety.
- Difficulties with processing information taking longer to do things can cause survivors to feel anxious in situations such as shopping.
- Communication difficulties slurred speech and problems with word-finding can cause anxiety if the survivor cannot express what they want or need to say.
- Incontinence a survivor may feel anxious about not being able to access a toilet in time when they are out.

In some cases, a lack of understanding from loves ones or others about the effects of brain injury can be a cause of anxiety. Activities such as shopping or returning to work can become a cause of anxiety if the survivor has had negative experiences of people not being understanding, kind or patient with them.

At times, brain injury can even be difficult for survivors themselves to understand, especially in the early days of injury. There may be changes in the way the survivor feels, thinks or processes things, and these can be difficult to make sense of without knowing about brain injury and its possible consequences. Going through such changes without understanding how or why they are happening can be a source of anxiety for many survivors.

Changes in relationships, employment status, financial circumstances Sustaining a brain injury can often have wide-reaching consequences, such as affecting independence, relationships, employment status and financial circumstances. Any of these changes can be a cause of anxiety for brain injury survivors.

 Independence - survivors may need help for things such as managing their finances, self-care or travelling. Relying on others to help with making such practical arrangements can cause anxiety, especially in the case of personal

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relationships, such as partners providing personal care. There can also be anxiety around dealing with external services such as care providers, or anxiety around the level or type of care they are providing. The psychological impact of loss of independence can also make some survivors feel anxious.

- Relationships many people report changes in their relationships after brain injury. While some relationships can strengthen, others may drift away, become tense or even completely break down. Relationships with colleagues may be changed, as well as relationships with neighbours or others in the community. These sorts of changes can cause anxiety for some survivors, especially if they result in a loss of a supportive network.
- Employment status many survivors struggle with returning to work after their brain injury. They may feel pressured to return before they are ready, or attempt to return but find that it is too difficult. These circumstances can cause anxiety for survivors, especially if they are unsure of what their options are or next steps to take.
- Financial circumstances a brain injury can have an impact on a survivor's
 financial circumstances. They may be unable to return to work, so no longer
 have the same level of income. Carers may also need to give up work to take
 on caring responsibilities. There might be extra expenditures, such as buying
 specialist equipment or making home adaptations. Survivors might need to
 apply for welfare benefits, which can be a stressful process that can cause
 anxiety.

Circumstances surrounding the injury itself

Some brain injury survivors might have high states of anxiety around circumstances relating to the injury itself, such as the experience of being treated in hospital, or if they have been involved in an accident. They might also experience strong emotional reactions in response to reminders or situations

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consistent with their injury, for example being in a car, travelling on public transport or going out at night. When these reactions are particularly strong, or where a person experiences flashbacks or other strong symptoms of anxiety, they might meet the criteria for a diagnosis of post-traumatic stress disorder (PTSD). PTSD is an anxiety disorder following traumatic events that can involve intrusive flashbacks, nightmares, sleeping problems and emotional effects that interfere with everyday life.

Brain injury survivors who are pursuing a compensation claim, or are involved in a legal case, might feel anxious about the outcomes. Giving evidence or testimonies might also cause anxiety.

Where can I get professional help for anxiety after brain injury?

There are a number of different professionals that can help with managing anxiety after brain injury, depending on its underlying cause.

You will usually need to speak to your **GP**, **neurologist or rehabilitation team** first to discuss getting help for your anxiety. Your GP might be able to prescribe suitable medication, or make a referral to an appropriate professional, depending on the cause of the anxiety.

If hormonal imbalances or other organic brain injury factors are causing anxiety, other professionals might get involved. For example, an **endocrinologist** can complete tests to measure hormone levels and advise on treatment that can help. **Neuropsychiatrists** can prescribe medication to improve anxiety symptoms.

Therapists such as **counsellors and psychotherapists** can offer talking therapies. These can help to explore the cause of anxiety, and therefore how to best deal with it. Therapists might be able to help with learning techniques such as breathing exercises to help when feeling anxious. It is helpful, if possible, to be seen by a therapist with knowledge of or experience in supporting people with brain injuries.

Clinical neuropsychologists are professionals that are experts in brain injury and its emotional effects, and can therefore offer the best type of specialist support for a range of issues relating to brain injury. The neuropsychologist will

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work with you, your family and maybe a close friend or colleague to develop a biopsychosocial formulation. This is a way of making sense of your personal experience by understanding the biological, psychological and social factors that contribute to your anxiety.

- Biological factors can include brain scans, details of the brain injury and results from tests.
- Psychological factors can include symptoms of anxiety, your own story, coping strategies and personal psychological difficulties.
- Social factors can include support from your family or friends, your community and your home environment.

This process will also help to identify areas of strength and coping.

If there are difficulties in relationships that are causing anxiety, **family therapists or counsellors** might be able to support by facilitating helpful discussions. Some psychologists and neuropsychologists have completed further training in couples work, psychosexual counselling and systemic therapy (a type of therapy that looks at family networks and relationships). There are also other therapies that look more deeply at relationships, such as Cognitive Analytic Therapy.

It is always important to check with your therapist or psychologist that they have the appropriate skills and training in supporting brain injury survivors to help you and your family. It is good practice to ask your therapist about their experience and skills, and why they think they would be the right people to help.

How can I cope with anxiety after brain injury?

We asked our online community of brain injury survivors and carers how they cope with anxiety after brain injury. Here are some of their top coping tips.

Learn tools and strategies to cope with anxiety

Try to practice taking deep breaths and learn breathing exercises, which can

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- help to calm your body down when you are starting to feel anxious. Guidance
 on breathing exercises is available on the NHS website at www.nhs.uk/
 www.nhs.uk/
 www.nhs.uk/
 <a href="mailto:mental-health/self-help/guides-tools-and-activities/breathing-exercises-for-stress.
 www.nhs.uk/
 mental-health/self-help/guides-tools-and-activities/breathing-exercises-for-stress.
- If you are out with others, or in a stressful environment, excuse yourself for a few moments and find somewhere quiet and peaceful to calm down.
- If you are having anxious thoughts about something in particular, try to shift your focus and attention onto something more positive, or get busy with something that you enjoy doing to distract yourself.
- Keep your Headway Brain Injury Identity Card with you when you are out, to help in situations where you need others to understand that you have had a brain injury. More information on the card and how to apply is available at www.headway.org.uk/supporting-you/brain-injury-identity-card.
- Try practicing mindfulness, which is a technique that keeps you focused on the present moment rather than worrying unnecessarily about the future. More information on mindfulness is available on the NHS website at www.nhs.uk/mental-health/self-help/tips-and-support/mindfulness. You can also check out our mindfulness training opportunities at www.headway.org.uk/about-brain-injury/professionals/training/mindfulness-breathing-exercises.

Manage the effects of brain injury to reduce anxiety

- Plan in advance where possible and where necessary. For example, if you
 feel anxious about your first day of returning to work since your injury, keep a
 list of things you need to take with you, a record of key dates and details, and
 set alarms where needed.
- Use equipment to help with coping with the effects of brain injury that might be causing the anxiety, such as noise-cancelling headphones if it is too loud in an environment, or communication aids to help with expressing what you want to share.

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 Some people find that substances such as caffeine can make their symptoms of anxiety worse, especially after brain injury. Often people drink caffeine as part of their normal routine, such as having a cup of coffee in the morning, or to help with managing fatigue. Try finding a balance with how much caffeine you consume, or try decaffeinated drinks where possible. Remember that caffeine can also be found in chocolate, energy drinks and some health supplements.

Talk to others

- Don't be afraid to ask for support from others. For example, if you are in a
 busy café, ask if you can be seated somewhere quieter. Or if you need
 someone to repeat what they have just said so that you can process it, or
 you have forgotten what someone has just told you, don't be afraid to ask
 them to say it again. Most people can be quite understanding if they know
 you need support.
- Share your feelings with someone that you trust and who you feel safe with.
 Remember that our helpline is available to provide a listening ear if you feel like you need to talk to someone about your feelings.
- Teach yourself, your family, friends and others in your life about brain injury to help them with understanding how you feel. Consider sharing other Headway publications with them to help them to learn about brain injury.
- Spend quality time with family, friends and people that matter to you, so that you feel well supported.

Change your perspective on life after brain injury

- Remember that brain injury can be a fluctuating condition, and how you are feeling today may well change in the future as you improve, learn to adapt and rebuild your life after brain injury.
- Set realistic expectations for new tasks and your recovery. Remember that some effects of brain injury can take weeks, months or years to improve, or may be lifelong and require adaptations to manage. Be kind to yourself, and

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celebrate achievements where possible.

• Gradually expose yourself to situations or things that trigger your anxiety, but always under the guidance of a trained professional.

Anxiety in carers

Carers of a brain injury survivor can develop anxiety as a result of the injury as well as the survivor themselves. Carers can include family, other relatives or friends. Some of the reasons that carers might develop anxiety are as follows:

- Needing to make travel and practical arrangements to visit the survivor in hospital;
- Seeing a loved one in hospital, especially if they are being treated in an intensive care unit;
- Coping with a reduced income if the carer is unable to return to work due to their caring responsibilities;
- Feeling concerns over the survivor's recovery and having fears for the future;
- Caregiver burden and responsibilities;
- Experiencing a negative impact on their relationship with the survivor and others (such as their own friendships).

While support for anxiety might be offered to brain injury survivors as part of their treatment or rehabilitation, it might not be as routinely offered to carers. However, carers can still contact their GP for a referral to appropriate psychological support, and the information in the previous section Where can I get professional support? is still largely applicable to carers, although support might differ slightly for young carers.

In addition, carers can access carer-specific support through organisations such as <u>Carers Trust</u>, <u>Carers UK</u> and other local carer support services.

Carers might also be eligible for a respite break or holiday to allow them time to relax and take a break from their caregiving responsibilities.

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More information about support for carers is available in our publication <u>Caring for someone with brain injury</u>.

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

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