

Mental health and brain injury - for carers



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

A brain injury can affect people's mental health in different ways, affecting quality of life, self-esteem, independence and relationships. Some mental health conditions can be managed by lifestyle changes and learning coping strategies, while other conditions will require professional treatment.

A brain injury can affect mental health in both brain injury survivors and their carers (family, partners, etc) in a number of ways.

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This publication offers information for carers of brain injury survivors on:

- getting support for their own mental health;
- supporting the brain injury survivor with managing their mental health.

Words in **bold and underlined** are defined in a glossary at the end.

Information on this topic specifically for survivors is available in our publication *Mental health after brain injury*, which describes what mental health is, how it can be affected by brain injury, where to get professional support from and how to cope. This is available on our website at www.headway.org.uk/information-library.

The information in this publication does not replace clinical guidance. You should always seek advice from a suitably qualified professional on managing the effects of brain injury. Your GP may be the best starting point for this.

You can also contact our nurse-led helpline for information and advice on living with brain injury on 0808 800 2244 or helpline@headway.org.uk.

What is mental health?

Mental health is a state of wellbeing that allows us to function and complete the activities that we want or need to do. It relates to how we think, feel, behave and cope with the world around us. Everybody has mental health.

Experiencing difficult life circumstances or poor health can affect our emotions and behaviour, making us scared, low or anxious. Sometimes this is short-term, and our emotions return to how they were once the stress stops. Some people may develop longer-term problems; if these get in the way of day-to-day life, they may be diagnosed as having a mental health or psychiatric condition.

It is possible for someone to have more than one mental health problem at the same time.

Below are some mental health conditions that brain injury survivors or carers can experience after brain injury, along with their symptoms:

- **Depression** – a persistent feeling of sadness or loss of pleasure accompanied by reduced appetite, reduced interest in activities, lack of

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energy, avoidance of socialising and tearfulness, among other symptoms. Depression can be classified as mild, moderate or severe. **Psychosis** can be experienced by some people with severe depression.

- **Anxiety** – a feeling of fear, worry or unease, which can cause feelings of restlessness and panicking. If someone has major and complex issues with anxiety, they may be diagnosed as having **generalised anxiety disorder**.
- **Post-traumatic stress disorder** – a form of intense anxiety in response to a highly stressful and traumatic life event, causing symptoms such as recurring flashbacks, nightmares and avoidance of anything that reminds the person of the trauma, among other symptoms.
- **Substance misuse** (alcohol, drug or medication use problems) – using alcohol, drugs and/or medication in a way that causes problems for the person themselves or others, sometimes to the point of dependence where it is difficult for them to cut down or stop, and they experience cravings and discomfort when they try.

Although often not considered a mental health problem in itself, lots of people with brain injury can struggle with excessive anger and irritability. This is a common effect of brain injury but can also be triggered by anxiety and depression. Getting treatment for mental health problems can often help with these feelings as well.

More information on anger and irritability is available in our publication [*Anger after brain injury*](#).

There are less common mental health conditions that can affect people with brain injury, such as **bipolar disorder**, **schizophrenia**, **psychosis**, compulsive behaviours, and eating disorders, to name a few.

Information on a range of mental health conditions, including symptoms, diagnosis and treatment is available on the NHS website at www.nhs.uk/mental-health/conditions.

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Looking after your own mental health

Brain injury doesn't just affect individuals with the injury; it can transform the lives of entire families. This is often referred to as the 'ripple effect' of brain injury.

Carers often need to make considerable changes to the way they live, such as spending less time with friends or reducing working hours. These changes can be difficult to adjust to. They can also affect the carer's sense of identity and personal life goals. Mental health issues such as depression and anxiety can be the outcome of these experiences.

If you are finding that your caring role has affected your mental health, remember that **help is available**.

Below are some suggestions for how to cope with your mental health.

Further information about your role as a carer after brain injury is available in our publication [*Caring for someone with a brain injury*](#).

Access professional support - you should start off by discussing any mental health concerns you have with your GP. Your GP might prescribe medication, or refer you to either talking therapies, support groups, mental health services or psychiatric services, depending on your needs.

If you feel nervous about getting help for your mental health, consider first contacting a mental health charity helpline service, a trusted relative or friend. This can help you to become familiar with having these conversations. Many of the organisations listed at the end of this publication have helplines or email services that you can contact.

Talk to others about how you are feeling - sharing your feelings with others can help you to feel less alone with your emotions and thoughts. It may also help others such as friends or colleagues to understand why your mood or behaviour may be different since you have become a carer. It can also be helpful to connect with others with similar mental health issues so that you can talk to others who understand your experiences.

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If you want to connect with other brain injury survivor carers, consider contacting your local Headway charity or volunteer-led branch, or using one of our online communities. More details on these are available on our website at www.headway.org.uk/supporting-you.

Learn about brain injury - learning about brain injury can help you to make sense of why things are difficult and can also help you to find ways to manage some of the changes that you are experiencing. Headway's publications can be a helpful starting point. These are free to access and cover a wide range of information on the effects of brain injury and tips for coping.

Be regular with medication - if you are taking prescribed medication to help with managing your mental health, make sure that you take your medication as prescribed and never change the dosage without first discussing this with your GP.

Recognise that things can and do get better after brain injury - experiencing a brain injury can cause significant life changes for everyone involved, that can be difficult to accept and adjust to, especially in the early days. However, try to remember that things can and do improve for many over time.

You could consider speaking to others affected by brain injury about how their life has improved over time, for instance by contacting your nearest Headway charity or volunteer-led branch, or visiting our website [Brain injury and me](#).

Consider your triggers - there may be certain factors that trigger your episodes of mental health, for example situations that make you feel anxious or locations that are associated with the trauma surrounding when the injury happened (such as being in hospital). Taking on a caring role can itself be a trigger, due to the stress of caring and changes in relationships or circumstances, which can sometimes lead to depression or anxiety. Work with family, close friends, therapists and local services to identify these and how best to cope.

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It might be helpful to keep a diary with dates and details of what you were doing on days when your mental health has been particularly affected. This can help you to identify both triggers and patterns, which might also be helpful with diagnosing some forms of mental health conditions, as well as giving you a space to express your emotions to help you recognise areas where you can develop coping strategies.

Try relaxation techniques - some mental health symptoms can be helped by learning relaxation techniques such as breathing techniques, mindfulness, meditation and spending time in nature. Use NHS' guide to breathing exercises for stress (www.nhs.uk/mental-health/self-help/guides-tools-and-activities/breathing-exercises-for-stress), NHS' guide to mindfulness (www.nhs.uk/mental-health/self-help/tips-and-support/mindfulness) and NHS' guide to meditation (www.nhs.uk/every-mind-matters/mental-wellbeing-tips/how-to-meditate-for-beginners).

Have a healthy lifestyle - having a healthy lifestyle includes getting enough good quality sleep, eating healthily and exercising.

Consider requesting support with your caring role, for instance asking family and friends to help out where they can, asking work to be flexible around your caring duties, or contacting your local adult social care team to find out about how they can support carers.

General tips for supporting the brain injury survivor with mental health

The type of support you offer to the brain injury survivor will depend on the condition they experience and the symptoms they have. For more information on this, see the publication *Mental health after brain injury*. Some general ways you can support the survivor are offered in this section, while support based on specific issues is offered further on in this section.

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The following general suggestions can help the survivor to feel better supported with their mental health after brain injury:

- **Encourage the survivor to access support from their GP.** Guidance on how to do this is available in the section *Encouraging the brain injury survivor to get support*.
- **Encourage the survivor to talk to you about how they are feeling.** Set time aside to regularly discuss this and check in if you have not heard from them for a while. Don't force them to talk if they don't want to – it might be that they are still processing their feelings about their change in circumstances and do not quite feel ready to share their thoughts.
- **Observe the survivor for changes to their behaviour.** Some brain injury survivors may struggle with recognising a mental health condition, or may be unwilling to get support. If you have serious concerns and the survivor will not speak with you about them, you may need to contact their GP or mental health services, depending on how serious your concerns are.
- **Try to identify triggers or patterns** to the survivor's mental health changes, and try to be sensitive to these. For instance, if outings trigger the survivor's anxiety, try to have a pre-formed plan to help them with this when outings are necessary. Try to also be mindful that the anniversary of the survivor's injury might be a particularly sensitive time for them. Consider planning positive or supportive activities during this time.
- **Remind the survivor to take medication** or complete therapy activities if they have problems with their memory. Consider setting alarms or keeping lists or calendars in easily accessible places to help.
- **Try not to dismiss the survivor's experiences or perspective** – they may

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have very different thoughts, feelings and experiences of the world, and you should avoid unhelpful comments such as “*don’t exaggerate*”, “*it’s not that bad*” or “*you’ll get over it.*” Even if the survivor is experiencing things that are not real, such as hallucinations, do not harshly challenge them - more guidance on this is available in the section *Supporting the brain injury survivor with other mental health problems*).

- **Keep details of emergency mental health services at hand** in case you need to contact these at any point, and encourage the survivor to do the same.

Supporting the brain injury survivor with depression

Depression is unfortunately a common experience after brain injury. You can read our publication [Depression after brain injury](#) to understand this better and support the survivor with using the suggested coping tips.

If the survivor is depressed due to their changed circumstances, try to reassure them that **things can and often do get better** for many after brain injury.

Work together to **identify coping strategies** and how to adapt activities so that they are still able to participate in things they enjoy and that give their life meaning.

Show **kindness, understanding, patience and encouragement** to help the survivor with feeling better supported. Learning more about brain injury and having honest conversations with the survivor can help you to better understand the ‘hidden’ effects of brain injury that may be causing them difficulties.

People with depression may occasionally self-harm as a coping mechanism. If you become aware of the survivor self-harming, try to speak to them calmly about their reasons for doing this and suggest getting help, for instance through their GP or support groups. You can also discuss ways in which they might be able to distract themselves when they feel the urge to self-harm.

Self-harming behaviour may be a way of coping with feelings of suicide. However, people can also have feelings of suicide without self-harming. If your loved one

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expresses suicidal feelings, try to assess their level of risk of harm. For instance, some people may express feelings of suicide but have no actual intention of attempting to take their own life, in which case you should gently encourage them to speak to their GP or contact a local mental health service.

If you have serious concerns that the survivor has a plan to take their own life, or they are in danger of making an attempt, you should contact their GP, their local mental health crisis team, or emergency services if the danger is immediate.

Supporting the brain injury survivor with anxiety

Anxiety is unfortunately a common experience after brain injury. You can read our publication [Anxiety after brain injury](#) to understand this better and support the brain injury survivor with using the suggested coping tips.

If the survivor is anxious due to their changed circumstances, try to reassure them that **things can and often do get better** for many after brain injury. Work together to identify coping strategies and how to adapt activities so that they are still able to participate in things they enjoy and that give their life meaning.

Encourage the survivor to learn breathing exercises or other relaxation techniques to help cope with anxiety episodes.

Show **kindness, understanding, patience and encouragement** to help the survivor with feeling better supported. Learning more about brain injury and having open and honest conversations with can help you to better understand the 'hidden' effects of brain injury that may be causing them difficulties.

Try to **identify what triggers the survivor's anxiety**, and work together to form plans to minimise the impact of these.

If you have concerns that the survivor has developed behaviours linked to their anxiety that may place them at risk to themselves or others, you should gently encourage them to seek support from health services, or contact local mental health services on their behalf if the risk is more serious.

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Supporting the brain injury survivor with other mental health problems

Although depression and anxiety are the most common forms of mental health problems after brain injury, brain injury can lead to an increased chance of developing a range of mental health problems.

The first place to ask for help is the GP, regardless of the type of mental health problem.

If the person is using alcohol or drugs in a way that is causing problems for you, themselves, or others, they may also benefit from contacting local community drugs and alcohol services.

In less common cases, mental health problems could involve seeing or hearing things that aren't there and having bizarre beliefs, known as **psychosis**. It can be unsettling to both experience, and be around someone having a psychotic episode. If the brain injury survivor is seeing or hearing things that are not real, or expressing thoughts and ideas that do not fit with reality, try not to panic or convince them that what they are experiencing isn't real. Instead, allow them to talk about what they are experiencing and how they feel about it. Ask if there is anything within reason that you can do to help or support them. Try to gently distract them by orienting them to things around them, suggesting activities or asking them to focus on their breathing.

You may notice your loved one's behaviour or actions change if they are experiencing a **manic** episode. They may have extreme emotions (including extreme feelings of happiness) or behave impulsively such as spending an excessive amount of money. They may talk very fast, seem more distractable than usual, be disinhibited, have difficulty sleeping and seem restless. Manic episodes are often temporary, lasting for anything from days to weeks or even months.

These are more serious types of mental health problems and require an immediate GP appointment. If you have concerns for the survivor or anyone else's safety, contact emergency services.

If you are not sure whether a change in behaviour, feelings or thinking is a type of mental health problem, it is best to get the situation assessed by a GP, or contact mental health charities for general information and guidance.

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Encouraging the brain injury survivor to get support

Brain injury survivors who are struggling with mental health issues should seek support from professional services. They may need encouragement to do this, especially if they are feeling nervous about reaching out or **lack insight** into their mental health symptoms.

If you are seriously concerned about the survivor's safety and believe they need immediate help, take them to the nearest hospital A&E or call 999.

If possible, try to remove them from any areas that may be dangerous for them, and stay calm. Speak reassuringly, and try to focus their attention on their surroundings. Stay with them if you can but remember to take care of yourself as well.

If helpful, suggest that the survivor reach out to a support service like [Samaritans](https://www.samaritans.org/) (116 123) or you can arrange for Samaritans to call them.

If your concerns are less urgent, or you are not sure what to do, the NHS' mental health symptom checker triage service at <https://111.nhs.uk/triage/check-your-mental-health-symptom> can guide you on what steps to take based on the survivor's symptoms.

You should talk to the survivor about how they are feeling and what you have observed. Try to choose a calm time, in a safe space free from distractions, when they are not feeling fatigued, in pain, or overstimulated. Respectfully listen to what they share and avoid dismissing their feelings; mental health challenges after a brain injury are often hidden, and you may not fully recognise how the survivor has been affected until they share this with you.

Encouraging them to visit their GP is a good next step. If they are hesitant, suggest they first talk with a supportive service, such as our nurse-led helpline or Samaritans. Think about issues that have been particularly problematic for them since their brain injury and offer direct examples of how the GP might be able to help with these. For example, if they are having particular difficulties with their mood or memory problems, their GP might be able to refer them onto a **neuropsychologist**. If they have the **capacity** to make their own decisions, and they have not been **detained**, remember that they have the right to choose whether or not to see a health professional.

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If the survivor chooses not to see their GP, but you still have valid concerns, you can share your observations directly with their GP. Although the GP cannot discuss your loved one's health details with you without their consent, they can take your concerns into account. If you are uncertain whether the GP will act on your input, or if you are worried for the survivor's safety, consider contacting their local mental health crisis team for further guidance.

Consider sharing this publication with the survivor to offer them information and advice for coping with their mental health.

Keeping yourself or others safe

If your loved one's mental health causes them to become violent, abusive or causes a risk of harm to themselves, yourself or others, there may be a need to seek intervention through a safeguarding team, the police, or local mental health services.

If you are in immediate danger, an emergency or think that your loved one might hurt themselves or others, call 999 and ask for the police.

In rare cases, if someone is seriously unwell and at risk of harming themselves or others due to a psychiatric condition, they may need to be **detained** in hospital for assessment and treatment under the **Mental Health Act**. This is done to keep themselves and others safe from harm.

During **detention**, a person will undergo assessment and may be medically treated. Family might be able to visit, but this will depend upon the hospital that they are being detained at and whether or not the person themselves wants visitors.

Further information on being detained is available on the NHS' website at www.nhs.uk/mental-health/social-care-and-your-rights/mental-health-and-the-law/mental-health-act.

In some cases, it might be necessary for your loved one to be treated in an inpatient mental health setting, such as a hospital or a crisis house. They might only be in for a short while, or for longer, depending on their care needs.

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Conclusion

This publication provides information and guidance for carers of brain injury survivors on how both the survivor's and their own mental health may be affected after the injury. We hope that you have found it a helpful resource and that it has given you suggestions of ways to cope with mental health problems after brain injury.

The organisations listed below can offer further guidance and support with mental health, while Headway's services can offer further advice and support on other aspects of living with brain injury.

Useful organisations

Hub of Hope – run by a charity called Chasing the Stigma, provides information on local mental health services in your area.

Web: www.hubofhope.co.uk

Headway's nurse-led helpline – offers information, supporting and a listening ear to people affected by brain injury

Tel: 0808 800 22244

Email: helpline@headway.org.uk

Web: www.headway.org.uk

Mind - a charity providing information and support people with mental health and wellbeing

Support line: 0300 102 1234

Infoline: 0300 123 3393

Welfare benefits line: 0300 222 5782

Legal line: 0300 466 6463

Email: info@mind.org.uk

Web: www.mind.org.uk

NHS 111 Check your mental health symptoms

<https://111.nhs.uk/triage/check-your-mental-health-symptoms>

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Web: www.headway.org.uk



Rethink Mental Illness – a charity providing information and advice for people severely affected by mental illness

Adviceline: 0808 801 0525

Email: advice@rethink.org

Web: www.rethink.org

Samaritans – a charity providing support for people experiencing a crisis or struggling to cope, including having suicidal feelings

Helpline: 116 123

Email: jo@samaritans.org

Web: www.samaritans.org

Shout – a text service for people experiencing a mental health crisis and needing support

Text: SHOUT to 85258

Web: www.giveusashout.org

Glossary

Bipolar disorder – a condition where a person experiences extreme mood swings, from intense highs (mania or hypomania) to deep lows (depression).

Capacity – the ability to understand information and make decisions.

Detained/detention– also called ‘sectioned’; being kept in hospital or other facility for assessment and treatment, sometimes against the person’s will if they lack capacity.

Generalised anxiety disorder - a persistent feeling of fear, worry or unease, which can cause feelings of restlessness, panicking, problems with sleeping and repetitive behaviours, among other symptoms.

Lack insight – being unable to observe and reflect on one’s own actions.

Mania – periods of extreme high energy, intense feelings of happiness and

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overactivity.

Mental Health Act – a piece of UK legislation that describes the rights of people with a mental health condition and how they should be treated.

Neuropsychologist - psychologists who are specially trained to assess and treat people with neurological conditions, including brain injuries.

Post-traumatic stress disorder - a form of intense anxiety in response to a highly stressful and traumatic life event, causing symptoms like recurring flashbacks, nightmares, and avoidance of anything that reminds the person of the trauma, among other symptoms.

Psychosis – a state of seeing and hearing things that are not based in reality.

Schizophrenia - a form of **psychosis** in which a person has thoughts and ideas that are not based in reality, such as hallucinations and delusions.

Substance misuse – a condition in which a person is unable to control their use of substances such as alcohol, drugs or medication.

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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.

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

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