



Brain injury: a guide for parents

Headway’s publications are all available to freely download from the [information library](#) on the charity’s website, while individuals and families can request hard copies of the booklets via the [helpline](#).

Please help us to continue to provide free information to people affected by brain injury by making a donation at www.headway.org.uk/donate. Thank you.

Contents

Introduction	1
The early days of injury	2
In the long-term	3
Common effects of brain injury	4
Issues commonly faced by parents	5
Emotional impact	5
Grieving for your son/daughter’s ‘old’ self	5
Loss of support	6
Becoming a carer again	6
Legal issues	6
Future arrangements	7
Coping strategies	7
Learn about your son/daughter’s brain injury and how you can help	7
Seek support	8
Communicate with one another	9
Look after yourself	9
Conclusion	10

Introduction

The relationship between a parent and their child is one of the strongest bonds that a person can have in their life. Parents are often deeply affected by hardships faced by their son/daughter, so when a brain injury occurs this can be a devastating and frightening experience for the survivor’s parent. On top of this, while it is normal for parents to feel concern for their child’s future, a brain injury can cause a parent to feel further fear and apprehension for their son/daughter’s abilities and prospects.



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

This factsheet received a Commended award at the British Medical Association Patient Information Awards 2019.

Patient information awards
Commended

improving life after brain injury



This factsheet has been written for you if you are the parent of an adult with brain injury. It contains information on how brain injury can affect your son/daughter, and offers tips that might be helpful for you as you go through each stage of your child's care.

If you are the parent of a young child with a brain injury, you can seek information and support from organisations such as [Child Brain Injury Trust](#), [The Children's Trust](#) or [Cerebra](#).

The early days of injury

The initial news of your son/daughter sustaining a brain injury can come as an immense shock and cause a wide range of emotions such as anxiety and fear. If your son/daughter lives nearby, it might be possible for you to immediately go to the hospital to visit them and stay by their side. It is, however, typical for most people to move to another city as they grow up, and as such you may not be able to easily visit your son/daughter at a time when you most want to be beside them.

Headway's Emergency Fund is a grant that can help to cover the cost of the immediate aftermath of brain injury, including travelling costs or overnight accommodation. For more information, visit www.headway.org.uk/supporting-you/headway-emergency-fund.

Early on, your son/daughter might be in a coma or reduced state of consciousness. There might be various machines attached to them, and their physical appearance might be changed, which can be very distressing for a parent to see. You will likely have many questions, but hospital staff might not be able to give you answers at this stage as it can be difficult to make an early prediction about recovery.

Even if your son/daughter is conscious, they might initially be displaying unusual or uncharacteristic behaviour such as swearing, shouting or being confused; this is known as post-traumatic amnesia (PTA). Although this can be upsetting, be assured that it is a normal stage of the recovery process and does usually get better over time. More information on PTA is available in the factsheet [Post-traumatic amnesia](#).

In any case, having a son/daughter in hospital with a brain injury can cause a range of emotions, including fear, helplessness, sadness and even grief. You might, however, also feel relieved if, for instance, they have survived an accident. Many people do not even know how to feel at this stage, and struggle with making sense of their emotions. This is okay, as there is no right or wrong way to feel during such a difficult time.

Here are some tips that can help you to cope at this stage:

- By instinct, you will likely want to spend most, if not all of your time, by your



son/daughter's bedside. However, this will leave you feeling exhausted at an already emotionally demanding time. It is therefore very important that you take time for yourself, rest regularly and eat healthily.

- If possible, hold your son/daughter's hand and ask nursing staff if there is any other way you can feel close to them (for instance, helping with care). This can provide you with physical comfort, and also help you to feel involved in their care, especially if they are in a coma or reduced state of awareness.
- Seek support from family members, close friends and Headway services. More information on how Headway can help, including details of our helpline, Emergency Fund and Acute Trauma Support nurses is available at www.headway.org.uk/supporting-you, or by contacting the Headway helpline on 0808 800 2244 or helpline@headway.org.uk.
- If your son/daughter has children and you are helping out with childcare, refer to the booklet [Supporting children when a parent has had a brain injury](#) for information and guidance.
- Learn about brain injury and hospital systems so that you are prepared for what stages might come next. This is especially important for the stage of planning your son/daughter's discharge from hospital. More guidance on these matters is available in the booklet [Hospital treatment and early recovery after brain injury](#).
- Following a discharge from hospital, your son/daughter might require input from rehabilitation services to help them with redeveloping skills that have been affected by the brain injury. Information on rehabilitation, including what to do if rehabilitation hasn't been arranged but you feel your son/daughter would benefit from it, is available in the booklet [Rehabilitation after brain injury](#).

In the long-term

It is sometimes thought that once a brain injury survivor is discharged from hospital, they will be back to their usual self in just a matter of time. While some survivors can continue to recover weeks or months after being discharged from hospital, it is also very common for the effects of the injury to become most noticeable once the survivor is back home and attempting to readjust to life after brain injury.

Following the discharge, some brain injury survivors find that they are able to return to their previous living arrangements, whether this is living independently or with a partner. For others, it might be necessary to move back in with their parents. This can take a



significant amount of adaption for both yourself and your son/daughter and you might need to make arrangements accordingly.

Either way, you will likely notice the effects of your son/daughter's injury as they develop over time. Indeed, 'hidden' effects of brain injury, such as emotional and cognitive effects might be more apparent to you than to other people, as you will likely know your son/daughter better than most. Hope for the future can sometimes give way to sadness and concern as the effects become more noticeable and start to affect your son/daughter's practical life and the relationships that they have with you and others.

The effects of brain injury, can however, continue to improve after the initial injury. Even if the effects continue, many people learn ways of adapting to these over time.

Common effects of brain injury

Brain injury can cause a range of effects that can change the way the brain injury survivor thinks, feels or behaves. It can also affect their skills and abilities. This section contains information about some of the common effects of brain injury. More information on many of these effects is available at www.headway.org.uk/information-library.

Physical effects

Fatigue	Difficulties with speech
Mobility issues	Epilepsy
Sensory impairment	Spasticity
Hormonal imbalances	Ataxia (irregular or uncontrolled movement)
Weakness or paralysis on one/both sides	Visual problems

Cognitive effects

Memory problems	Problems with motivation
Reduced concentration	Reduced information processing
Reduced problem-solving	Repetition or 'perseveration'
Impaired reasoning	Impaired insight and empathy
Impaired visual-perceptual skills	Language loss (aphasia)



Emotional and behavioural effects

Personality changes	Loss of confidence
Mood swings ('emotional lability')	Depression and sense of loss
Anxiety	Frustration and anger
Abusive or obscene language	Disinhibition
Impulsiveness	Obsessive behaviour

Issues commonly faced by parents

Emotional impact

In the early days, a brain injury can leave parents worrying for their son/daughter's future. Parents might question whether their son/daughter will be able to work, have a relationship or a family, and be independent. A brain injury can affect some or all of these aspects of life, although many survivors do of course go on to make a good recovery, regain independence and achieve a range of personal life goals.

Emotions such as sadness, grief, anxiety and anger are commonly experienced by parents. However, positive emotions such as relief, hope for the future and pride in a son/daughter's recovery and achievements are also typically felt.

The experience of seeing a son/daughter in hospital can also be highly distressing for many parents, and you may find that thoughts of your son/daughter being in hospital continue to trouble you for weeks, months or even years after their discharge. If this becomes problematic, consider seeking professional support, for instance from a counsellor or psychotherapist. You could also contact the Headway helpline on 0808 800 2244 or helpline@headway.org.uk (Monday-Friday, 9am-5pm) to get emotional support.

Grieving for your son/daughter's 'old' self

You may find that the effects of your son/daughter's brain injury change the way they think, feel and behave. This can result in an overall change in their personality, which can be upsetting for people who previously knew them well, and particularly distressing for parents. There may be times when you feel that there are traces of your son/daughter's 'old' self that are still there, but only occasionally, and you may question whether they will ever be the same person again.

Such thoughts can often result in a sense of loss or grief experienced by both the survivor themselves and their parents. While some survivors and their parents gradually come to accept their new life and sense of self, many others continue to reflect over the person they were before their injury. It is important to seek support when dealing with grief, either



from close friends and/or professionals, as struggling through these feelings alone can sometimes cause ongoing feelings of loneliness and depression. Remember as well that it is possible to move forward creating new memories together once you are both ready.

Loss of support

Many people depend on their families for support and this is also true of parents and their children. When a brain injury occurs, the son/daughter may no longer be able to offer the same level of practical or emotional support to their parent. Loss of empathy after brain injury can be particularly detrimental to many relationships in the survivor's life, especially those they have with their parents.

In addition to the loss of support from your son/daughter, some parents feel that their own friends begin to drift away as a result of being less able to spend time socialising. In such cases it can help to talk to friends about your experiences so that they understand what you are going through and why you might be less able to spend time with them. You could also consider speaking to other families going through similar experiences, for instance, through your nearest Headway group or branch, or Headway's online community HealthUnlocked. For more information on this, see the section *Coping strategies*.

Becoming a carer again

When your son/daughter was young, you probably cared for them every day and tasks such as feeding and dressing them were probably a part of your daily routine. After a brain injury, you may find yourself supporting them with these tasks again, especially if you are living with them. Even if your son/daughter is physically independent, they might need support with activities that rely on their memory, attention and organisational skills.

Adapting your role to include caring for your son/daughter again can be an upsetting experience. Indeed, any changes in roles following a brain injury can be difficult to adjust to. Your son/daughter might also be frustrated at having lost their independence, and may direct anger towards you out of frustration. If this is the case, and you are concerned about anger episodes, refer to the factsheet [Managing anger: tips for families, friends and carers](#).

The change in your role might mean that you have to reduce your working hours, or give up work completely. You may also find that you have less time to yourself. As a result, you may have less time to spend with your friends or doing activities that you enjoy. Indeed, many carers report feeling socially isolated, and often receive little or no support and understanding from friends and other family members. The strategies provided in the following section might be helpful with managing this change in your role.

Legal issues

Your son/daughter may no longer have the capacity to make important decisions for



themselves, such as how to manage their money. In this case, you might consider appointing a deputy for them, or taking this role on yourself. Being a deputy gives someone the legal right to make certain decisions on behalf of a person who lacks capacity, under the framework of the Mental Capacity Act. More information on what becoming a deputy involves and how to apply for deputyship is available in the booklet [Mental capacity: supporting decision making after brain injury](#).

Future arrangements

Parents may feel concern for their son/daughter's future, especially if they are elderly and/or their son/daughter's primary caregiver. For instance, they might worry about what financial and practical arrangements will be made for their son/daughter when they are gone. If you have such concerns, consider talking to family/close friends about future arrangements, researching what services your local council can offer, and writing a will. Headway offers a free will writing service; more information on this is available at www.headway.org.uk/donate/a-gift-in-your-will.

Further information on making future arrangements is available in the Headway factsheet *Ageing carers*.

Coping strategies

Remember that brain injury affects people differently, so some of the following coping strategies might be more relevant to yours and your son/daughter's personal circumstances than others.

Learn about your son/daughter's brain injury and how you can help

- Refer to Headway publications to learn about the effects of brain injury and how you can help your son/daughter to manage these on a daily basis. Headway publications are available on www.headway.org.uk/information-library or by contacting the helpline on 0808 800 2244 or helpline@headway.org.uk (Monday - Friday, 9am - 5pm).
- Offer help to your son/daughter if you notice that they are consistently struggling with a task or cannot do something safely, but do not rush to do everything for them. Instead, if they are able to do so safely, give them time and opportunities to challenge themselves, as this can be an important part of their rehabilitation.
- Respect your son/daughter's privacy, and don't feel like you have to be with them all of the time or check up on them every day. This is as important for you as for them, as it means you are both able to spend some quiet time alone,



even if this is just for a few minutes a day.

- Speak to rehabilitation staff about activities or exercises that you can help your son/daughter with outside of therapy sessions. You might even be able to carry out such activities over the phone, for instance encouraging your son/daughter to talk about what they did during the day to help with memory problems.
- For general guidance and suggestions on tasks and exercises that you can do with your son/daughter, refer to the booklet [Redeveloping skills after brain injury](#).

Seek support

- Seek support from relatives and close friends where possible. For instance, relatives can help by spending time with your son/daughter a few times a week, and friends can help by allowing you to talk about how you are feeling. Family or friends can also help in practical ways such as bringing cooked meals around or offering to do some grocery shopping.
- Seek information and support from the Headway helpline on 0808 800 2244 or helpline@headway.org.uk (Monday - Friday, 9am - 5pm). If you are an internet user, you can also visit Headway's online community at www.healthunlocked.com/headway. Headway's network of groups and branches are also available to offer local support. You can find details of your nearest Headway group or branch by visiting www.headway.org.uk/supporting-you, or contacting the helpline.
- If you are struggling with supporting your son/daughter with day-to-day tasks such as washing and dressing, contact your local adult social care team as they might be able to arrange for someone to come and help. Details for local adult social care teams are available on local council websites.
- Depending on how much care you are providing for your son/daughter, you might be eligible to receiving financial support through the benefit Carer's Allowance. You can find out more about this in the booklet [A guide to welfare benefits after brain injury](#).
- If you need emotional or psychological support, consider speaking to your GP about getting a referral for talking therapy, such as through a counsellor or psychotherapist. You can also find a directory of private therapists on www.itsgoodtotalk.org.uk.



- Encourage your son/daughter to speak to their GP about any further rehabilitation they may require to help with physical, cognitive, behavioural or emotional problems after their brain injury.

Communicate with one another

- Try to encourage your son/daughter to talk to you about how they are feeling. As a parent, there may be things they feel they can only talk to you about. On the other hand, there may be topics that may not be comfortable for them to discuss with you, or you with them. In this case, encourage them to speak to their friends, other relatives or relevant professionals.
- Consider asking your son/daughter to express their feelings using letters, art or creative writing. This can be therapeutic for many people, and can also make it easier for some survivors to share feelings they would otherwise struggle with expressing.
- If appropriate, and with your son/daughter's agreement, try to stay in touch with other people in their life, such as close friends and partners. This can help to ensure that you are all sharing information with one another, which can create a closer, more supportive network around your son/daughter.
- If you have other children, make an effort to spend time alone with them and ask how they are coping. Siblings of a brain injury survivor can sometimes be overlooked, despite the fact they are likely to be affected by their sibling's injury as well. You could also consider directing siblings to the factsheet [Brain injury: a guide for siblings](#).

Look after yourself

- If you are caring for your son/daughter, try to make sure that you set some time aside for yourself on a regular basis and do not feel guilty about this. You could also consider making arrangements for respite care. More information on this is available in the booklet [Caring for someone after a brain injury](#).
- If you are an older parent, you might have been relying on your son/daughter to assist with looking after you in your later years. Needing to now look after them instead may cause you to feel anxious about your own future. If this is the case, or you are concerned for planning your old age, consider contacting organisations such as Age UK or your local Citizens Advice for advice and support with making appropriate arrangements.



Conclusion

Having a son/daughter sustain a brain injury can be a frightening experience, and over time you will probably notice how their injury has affected them. Your son/daughter may rely on you more than others for both practical and emotional support. It is important for you to take time to look after yourself in between.

It is hoped that the information in this factsheet has helped you, as a parent to make sense of your feelings and experiences, and to understand how you can support your son/daughter as well as yourself.

Acknowledgements: many thanks to the parents of brain injury survivors who provided guidance and feedback on this factsheet.

To discuss any of the issues raised in this factsheet, or to find details of our local groups and branches, contact the Headway helpline on 0808 800 2244 or helpline@headway.org.uk (Monday - Friday, 9am - 5pm).

Please tell us how helpful this publication has been by filling in our short survey at www.surveymonkey.co.uk/r/hwpublications.

Factsheet first published 2018. Next expected review 2020.

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