

Siblings' guide to brain injury



This publication is part of Headway's *Family and relationships issues* 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.

Introduction

Siblings usually share experiences while growing up, which often creates a close relationship between them. Even if siblings are not close, or grow apart over time, their family ties mean that they often share a lifelong relationship, and may come together in times of difficulty, such as if a brain injury has been sustained.

It can be a very difficult experience to have a sibling sustain a brain injury. The non-injured sibling may struggle with making sense of the circumstances or their own feelings, and wonder what they can do to help their injured brother or sister. Their own support needs can often be overlooked by family and professionals, who may be entirely focused on the injured sibling. Siblings may also live far apart, making visits difficult or even impossible.

This publication has been written to offer information to the siblings of a brain injury survivor. It also offers tips for how to support your sibling and how to look after yourself through this difficult time.

The early days of injury

The period immediately following your sibling's injury can be a frightening and confusing time. The outcome can be very uncertain and it might be the first time you have had any experience of brain injury. Hospital staff might be unable to give you or your family answers to questions that you have at this stage, which can leave you feeling very worried, especially if your sibling is in a coma or reduced state of consciousness. More information on these states is available in our publication [Coma and reduced awareness states](#).

When your sibling regains consciousness, they might initially be displaying unusual or uncharacteristic behaviour, known as post-traumatic amnesia. Although it can be distressing to see your sibling in this state, be assured that it is a normal part of the recovery process. More information on this is available in our publication [Post-traumatic amnesia](#).

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During this time, you might feel emotions such as sadness, fear, worry and stress, although you might also be relieved if, for instance, your sibling has survived an accident. You might not even know how to feel. This is okay, as there is no right or wrong way to feel during such a difficult time.

What can you do to help?

- Refer to our publication [*Hospital treatment and early recovery after brain injury*](#) for general information about this stage.
- Arrange a visiting rota with the rest of your family so that you can take turns with spending time with your sibling.
- When visiting your sibling, try not to overwhelm them with too much information or engage them in lengthy discussions, as they might struggle with fatigue or processing information.
- If your sibling has children, offer to take them with you on hospital visits, if this is appropriate, or help with looking after them. More information on supporting children during this time is available in our publication [*Supporting children when a parent has had a brain injury*](#).
- Provide your sibling's friends with updates, for instance through the use of social media or Headway's website *I'm Calling about Chris* at www.callingabout.org.uk. Keeping friends informed and involved can help to ensure that your sibling is still a part of their social network, which can be helpful in the long-run.
- Don't forget to look after yourself during this time. This might be difficult, as you will likely be preoccupied with thoughts of your sibling. However, do try to maintain your hobbies, interests and regular routine if possible, and remember to take some quiet time out to relax by yourself as well.

In the long-run

It is often assumed that once a brain injury survivor is out of hospital, they will make a full recovery in just a matter of time. However, it is common for the

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effects of the injury to develop and become most apparent once the survivor is back home. Below are some of the common effects of brain injury that your sibling might experience over time.

Physical effects

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

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

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Regardless of whether you live with your sibling or not, you will likely notice these effects and experience changes in your life, for instance needing to visit your sibling more often than you did before their injury or helping out with tasks such as shopping or childminding. If you are close to your sibling, you might even be providing care for them.

Further support from other services may be needed by your sibling, for example ongoing rehabilitation, practical support with day-to-day functioning, financial support or support with socialising. Encourage your sibling to speak to their GP about any referrals they may require, or to contact their local adult social care team if they need support with activities such as washing, dressing and preparing meals.

Tips to help your sibling

- **Learn about brain injury**

Read about the effects of brain injury and speak to your sibling about which effects they personally experience. Headway's publications offer information on different effects of brain injury and are available to download for free at www.headway.org.uk/information-library.

- **Encourage your sibling to learn about brain injury**

Some brain injury survivors feel that they are not given enough information about brain injury and how it might affect them on a long-term basis. If your sibling feels this way, encourage them to read relevant Headway publications, or provide them with publications to read whenever they feel ready.

- **Help out with rehabilitation activities**

If appropriate, ask rehabilitation staff whether you can help your sibling with activities and exercises outside of therapy sessions.

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- **Encourage your sibling to seek support from Headway services**
Headway groups and branches offer local support to brain injury survivors. You can encourage your sibling to make contact with their nearest Headway group or branch, or make enquiries on their behalf. To locate your sibling's nearest Headway group or branch, visit www.headway.org.uk/supporting-you. The Headway helpline is also available to offer information and emotional support on 0808 800 2244 (Monday-Friday, 9am-5pm) or helpline@headway.org.uk.
- **Spend time alone with your sibling**
Try to spend some time alone with your sibling, and use these moments to talk about how you are both feeling. Siblings are sometimes able to talk to one another about things that they might otherwise find difficult to share with other family members or friends. Consider doing relaxing activities while spending this time together, such as going for a walk or sitting in a park. This might help to make your sibling feel more relaxed and able to open up about their feelings, and this can also create special memories together.
- **Discover new activities to do together**
Your sibling may struggle with, or no longer be able to do activities that you did together before their injury. If this is the case, discover new activities that you can do, or try to modify previously enjoyed activities so that your sibling can now do them safely and comfortably.
- **Don't take it personally if your sibling's behaviour towards you is different**
Brain injury can change many aspects of a person's life, and can affect their emotions, skills and hopes for the future. It can also often change the survivor's personality. If your sibling is behaving differently towards you, try not to take this personally. Give your sibling time to make sense of their circumstances, and remind them that you are there to support them. They may not accept your support in the early days, but may well seek this later on.

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- **Offer support at appointments or assessments**

Consider attending GP appointments, welfare benefits assessments or other such meetings along with your sibling. You could also help them with filling in relevant initial paperwork. This can be helpful if your sibling struggles with expressing how their injury has affected them, forgets key issues or if they have a lack of insight (more information on this is available in our publication [*Insight and awareness after brain injury*](#)).

Educate others

Your sibling's friends may not know about how brain injury can affect someone, and as a result they might start spending less time with your sibling or stop seeing them altogether. This can be deeply upsetting for many brain injury survivors. With your sibling's permission, consider encouraging their friends to read our publication [*Friends' guide to brain injury*](#).

Caring for yourself

Many family members report feeling concerns for the future of their injured relative, especially if they are no longer able to return to work or drive. Such concerns for your sibling might cause you to feel anxious, depressed, stressed or frustrated. You might also feel saddened by the change in your sibling, and even be experiencing a sense of grief for their old self. Practical changes in your life, for instance if you have to take on extra responsibilities, might leave you feeling stressed and tired.

It is important that you try to look after yourself through this time, and if you do need support, don't be afraid to ask. Here are some tips that might help you with caring for yourself.

- **Be honest with yourself about your emotions**

Remember that emotions such as anger, sadness, guilt and fear, are natural responses, so allow yourself to be honest about how you are feeling. It might help to use creative ways of expressing your emotions, such as keeping a diary or experimenting with art.

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- **Take time out for yourself**

Try to set aside time to relax by yourself each day. You could consider letting other family members or your sibling know that you are resting during this time so that you are not needlessly disturbed.

- **Talk to people**

Talk to others such as family members or close friends about what you are going through and how you are feeling. This can help others to understand, provide support and make allowances where necessary, for instance if you are less able to commit to attending social events.

- **Seek support**

Although siblings are not routinely offered support by services, this does not mean you cannot seek support if you feel you need it. You can make contact with the Headway helpline if you need emotional support or just to talk to someone about what you are going through. The helpline is available on 0808 800 2244 (Monday-Friday, 9am-5pm) or helpline@headway.org.uk.

If you are deeply distressed by your sibling's injury, you could consider attending counselling sessions. You can request this even if your sibling's injury was a long time ago, as some siblings report being affected by the memories of their sibling's injury years later. Speak to your GP about getting a referral.

- **Take a break from caring**

If you are providing care for your sibling, ask other family members to help out where possible. You could also consider taking a break from caring by arranging for respite care. More information on this is available in our publication [*Caring for someone with a brain injury*](#).

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Conclusion

It can be a very difficult and upsetting experience to have a family member experience a brain injury. Siblings might find themselves experiencing a range of emotions and practical changes, and may not be receiving support through this difficult time.

It is hoped that the information in this factsheet has helped you, as a sibling, to learn more about how to support your brother or sister and also how to look after yourself, both in the early days and in the long-run.

More information about how relationships are generally affected is available in our publication [*Relationships after brain injury*](#).

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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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