

Grandparents' guide to (adult) 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.

Contents

Introduction	1
The early days of injury	2
In the long-run	3
The impact of brain injury and tips to help	4
Tips for helping the family	5
Tips to help yourself	5
Practical considerations	6
Conclusion	7

Introduction

When a person sustains a brain injury, partners, siblings and parents are often the main relatives to be involved in hospital meetings and decisions regarding care. As a grandparent, this might leave you feeling uninvolved and removed from your grandson/ granddaughter's treatment, resulting in a sense of helplessness when you want to be there for your family.

On the other hand, you might find that you start to take a more active role in your grandson/ granddaughter's life, for instance if you spend time caring for them. You may also spend more time supporting the family in everyday life, especially once your grandson/ granddaughter has returned home.

Brain injury affects not just the brain injury survivor themselves, but also the whole family network around them. This publication has therefore been written to help you as a grandparent with understanding how brain injury can affect your relationship with your grandson/ granddaughter, and to offer suggestions of how you can support them, the rest of the family, and yourself.

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

The early days of injury

Having a relative in hospital with a brain injury can be a frightening experience for family members. If it is your grandson/ granddaughter who has sustained the injury, your immediate concern will be for them, as the love of a grandparent is often as strong as the love of a parent. However, you will likely also be concerned for your son/ daughter, who will be anxious and fearful for their own child's condition. You may therefore find that you are required to put your own fears for your grandson/ granddaughter aside in order to support your son/ daughter.

You are likely to have questions when your grandson/ granddaughter is in hospital, particularly in the early stages of their injury or if they experience a loss of consciousness. If you are unable to visit your grandson/ granddaughter in hospital then you may rely on family members to share information with you. This can lead to anxiety and frustration if you find yourself waiting for significant periods of time for information to be passed on.

Even if you are able to visit your grandson/ granddaughter in hospital yourself, staff may not have answers to questions that you or your family have at this stage, as it can often be very difficult to predict the outcome of brain injury. Remember though that staff will share as much information as they can with your family, as soon as they are able to.

Below are some suggestions that may help to cope with this early stage:

- Refer to Headway publications to learn more about brain injury and hospital systems, such as our publication [*Hospital treatment and early recovery after brain injury*](#).
- Find out more about how Headway can help during this time by visiting the 'Supporting you' page of our website: www.headway.org.uk/supporting-you or by contacting the Headway helpline on 0808 800 2244 (Monday - Friday, 9am - 5pm).
- If you are unable to visit the hospital yourself, write down any questions that come to you through the day and ask whether a relative visiting your grandson/ granddaughter can ask on your behalf.

Helpline: 0808 800 2244

Email: helpline@headway.org.uk

Web: www.headway.org.uk

- Seek support from other family members or close friends, especially if you are providing emotional support to your son/ daughter through this time.
- Your son/ daughter or perhaps your grandson/ granddaughter's partner might be required to make or be involved in decisions of treatment, and might turn to you for advice. This can be a very emotionally difficult experience for everyone, and opinions may differ. Try to support one another through this difficult time. If you disagree with a decision, try to gently talk through this, but respect other's opinions.

In the long-run

Your grandson/ granddaughter may need to spend time in a rehabilitation unit after being discharged from hospital. During this period they will work with a rehabilitation team to try and relearn skills that will help them to live independently, or partly independently, when they arrive back home.

The changes that a brain injury can bring to your grandson/ granddaughter's life will probably become most apparent when they actually return home after a discharge from hospital or rehabilitation. They may still require significant support with everyday tasks such as feeding or bathing themselves, or their speech or ability to walk may be affected. A partner, parent or yourself may be able to provide the required support. However, providing such intense support can be challenging and often requires a great deal of time and patience. If your son/ daughter or grandson/ granddaughter's partner are providing most of the support, especially during the early stages, your own support may be better directed to them than to your grandson/ granddaughter.

If your grandson/ granddaughter is living independently and still needs support, and it is not possible for the family to provide the level of support required, consider contacting their local council for a needs assessment.

Anyone providing care for a brain injury survivor who appears to have a need for support is also entitled to support under the Care Act (2014). More information on this is available in our publication [*Caring for someone with a brain injury*](#).

Helpline: 0808 800 2244

Email: helpline@headway.org.uk

Web: www.headway.org.uk

The impact of brain injury and tips to help

The effects of brain injury can be psychological, emotional, cognitive and behavioural. They are not always visible. You may therefore find that though your grandson/ granddaughter looks as though they have made a good recovery once they return home, they are not their usual self. As a result, your relationship with them may be different following an injury.

Suggestions of what to do to support your grandson/ daughter and look after yourself in the meantime are as follows..

- Your grandson/ granddaughter may no longer be able to visit you as frequently or for as long as they did before their injury. Try not to feel disheartened by this, as brain injury can result in people having problems with fatigue, memory, emotions or feeling motivated (among others), and any of these issues can cause difficulties with making visits. If possible, try to arrange visiting them yourself, or arrange visits at times that suit your grandson/ granddaughter best.
- Do remember that having a brain injury can bring many changes to a person's life, for example no longer being able to work or drive. Your grandson/ granddaughter may therefore need to take time with processing and accepting their new life and sense of self. You will naturally be concerned for their wellbeing, but try to give them space if they need time to adjust to their changed circumstances, and offer them a 'listening ear' if they need it.
- You may have had favourite activities that you undertook with your grandson/ granddaughter that they are no longer interested in or able to safely do. This might be upsetting, but do not try to force your grandson/ granddaughter back into an old routine. Instead, find new activities that you can enjoy together when they are ready, or spend time with them when they are undertaking activities that they personally enjoy.
- You might find it useful to engage your grandson/ granddaughter in meaningful activities that can help with their recovery. For instance, you can ask them to help with shopping for groceries, which might help with

Helpline: 0808 800 2244

Email: helpline@headway.org.uk

Web: www.headway.org.uk



developing memory skills. Another idea might be to ask them to help with assembling something to practice following instructions, or doing a word/number puzzle to practice focusing. More suggestions are available in our publication [*Redeveloping skills after brain injury*](#).

- Remember that the effects of brain injury can take weeks, months or years to improve and some effects might even be lifelong. Celebrate any small successes in your grandson/ granddaughter's recovery and encourage their parents or partner to do the same. If you are concerned that your grandson/ granddaughter's effects are not improving or are getting worse over time, encourage them to speak to their GP.

Tips for helping the family

There are a number of other ways that you can help out by taking on some of the day-to-day responsibilities that your son/ daughter or grandson/ granddaughter's partner are struggling to do or no longer have time to do. How much you are able to help out will depend on your own abilities and availability, but some suggestions of ways in which you can help are listed below:

- Offer to do the family's grocery shopping, or pick up a few items for them when you're out doing your own. You could also take meals over to the family if they are struggling to find time to cook.
- Offer to do the gardening for them, even if that just involves keeping things tidy or cutting the grass.
- Offer to accompany your grandson/ granddaughter to appointments. You could also attend a Headway group or branch with them, as these are often to families of brain injury survivors as well as the survivor themselves.
- Offer to help out with tidying or cleaning the house.

Tips to help yourself

- Be honest with yourself about how you are feeling. Emotions such as fear for your grandson/ granddaughter's future, sorrow at their injury, relief if they

Helpline: 0808 800 2244

Email: helpline@headway.org.uk

Web: www.headway.org.uk



have survived a traumatic incident or possibly even guilt, however unjustified, over the experiences they have gone through are all natural responses to a loved one sustaining a brain injury. It is important to understand that there are no right or wrong emotions to feel during this time.

- Consider getting support from your nearest Headway group or branch, our nurse-led helpline or online communities. More information is available on the 'Supporting you' section of our website at www.headway.org.uk/supporting-you or by contacting the helpline on 0808 800 2244 (Monday - Friday, 9am—5pm) or helpline@headway.org.uk.
- Keep your own friends aware of what's going on and how you are feeling. You will naturally be more occupied with your own family during this time, so it can help to make friends aware of why you might not be around for them as much.
- Don't forget to look after yourself during this time, by eating well and getting good quality sleep and regular exercise.

Practical considerations

- Be aware that a brain injury can, in some instances, affect a person's judgement and their ability to manage their own finances effectively. They may have a deputy appointed to manage finances on their behalf. These might be important things to consider if you are thinking about leaving your grandson/ granddaughter a gift in your will.
- If you are considering buying a gift for your grandson/ granddaughter, think of items that might help with any particular difficulties they have, such as notebooks for memory problems or easy-to-use mobile phones. Nowadays there are lots of electronic gadgets that can assist with various different effects of brain injury, so take some time to research what is available and what could be suitable.
- You may find that you need to provide more support to your son/ daughter than your grandson/ granddaughter. Try to spend quality time with them to find out how they are feeling, and encourage them to share their feelings with

Helpline: 0808 800 2244

Email: helpline@headway.org.uk

Web: www.headway.org.uk



you. As their parent, they may feel they can be more open with you than anyone else.

Conclusion

Having a grandson/ granddaughter experience a brain injury can be extremely difficult, and there is no right or wrong way to feel. It is important to remember that everyone's experience with brain injury is different. We hope that the information in this publication has helped with making sense of the changes that can take place when a grandson/ granddaughter experiences a brain injury, and what you as a grandparent can do to help them, yourself and the rest of the family.

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.

First published 2017. Next review 2024.

Helpline: 0808 800 2244

Email: helpline@headway.org.uk

Web: www.headway.org.uk