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## Brain injury: A guide for grandparents

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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](http://www.headway.org.uk/donate). Thank you.

### 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 may 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 factsheet 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.

### When a grandson/granddaughter is in hospital

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 many questions when your grandson/granddaughter is in hospital,



particularly in the early stages of their injury or if they experience a loss of consciousness, or coma. 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. Information on hospital systems is available in the Headway booklet [Hospital treatment and early recovery after brain injury](#). Information about coma and reduced awareness states is available in the factsheet [Coma and reduced awareness states](#). Contact the Headway helpline on 0808 800 2244 or [helpline@headway.org.uk](mailto:helpline@headway.org.uk) to receive free print copies of these and other publications.
- The nurse-led Headway helpline and Headway's network of groups and branches are also available to answer offer information about brain injury and emotional support to you or other family members. For more information, visit [www.headway.org.uk/supporting-you](http://www.headway.org.uk/supporting-you) or contact the helpline on the above contact details for help with locating your nearest group or branch.
- If you are unable to visit the hospital yourself, write down any questions that come to you through the day and suggest that a relative visiting your grandson/granddaughter asks the hospital team questions on your behalf.
- Consider writing a letter to your grandson/daughter to read if they are conscious, or for another relative to read to them if they are in a coma. Try to keep information basic, as they might have difficulties with fatigue or information processing at this stage.
- The Headway Emergency Fund may be able to cover the cost of emergency expenditures in the immediate aftermath of a brain injury, for instance if you are struggling with the financial cost of visiting your grandson/granddaughter in hospital. For more information, visit [www.headway.org.uk/supporting-you/headway-emergency-fund](http://www.headway.org.uk/supporting-you/headway-emergency-fund).



- 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, if they have one, may be required to make or be involved in decisions of treatment and they 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 others' opinions.

## Supporting a grandson/granddaughter when they come home

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 a rehabilitation unit. 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 you 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. Local authorities throughout the UK have an obligation under the Care Act (2014) to carry out an assessment and make provisions for requirements that your grandson/granddaughter may have.

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). You, your son/daughter, or your grandson/daughter's partner may therefore wish to ask for a carer's assessment from the local authority if support is needed with the caring role. More information on this is available in the Headway booklet [Caring for someone with a brain injury](#).



## The impact of brain injury and tips to help

The effects of brain injury can be psychological, emotional, cognitive and behavioural, and are not always physically visible - indeed, brain injury is often called a 'hidden disability' for this reason. You may therefore find that although your grandson/granddaughter physically 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 their injury. This can be a very difficult thing to accept and deal with, and more information on how relationships are generally affected following brain injury is available in the Headway booklet *Relationships after brain injury*.

Suggestions of what to do if you feel that your relationship with your grandson/granddaughter has changed are offered below.

- 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, and any of these can affect a person's ability to make visits. If possible, try to arrange visiting them yourself, or arrange visits at times that suit your grandson/granddaughter.
- 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 might 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 new circumstances.
- You may have had favourite activities that you undertook with your grandson/granddaughter that they are no longer interested in or able to 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 or spend time with them while they are undertaking hobbies 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 may help with developing memory skills whilst also providing much-needed respite for your son/daughter or grandson/granddaughter's partner. Another idea might be to ask them to help with assembling something or simply doing a word or a number puzzle. This can help to improve the ability to follow instructions or focus on tasks. More suggestions are available in the Headway booklet [Redeveloping skills](#).



- 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 walk the dog, or volunteer to 'pet-sit' for any pets that your grandson/granddaughter or their parents have. This can be particularly useful during times when your grandson/granddaughter gets fatigued.
- Offer to accompany your grandson/granddaughter when attending appointments, such as visiting their GP or welfare benefits advisor. You could also attend a Headway support group or branch with them.
- Provide additional assistance with the childcare of any younger children in the family, such as your grandson/granddaughter's younger siblings.
- Offer to help out with tidying or cleaning the house.
- Invite the family or just your grandson/granddaughter over for a few hours. This can provide some respite care for your son/daughter or your grandson/granddaughter's partner.
- If your son/daughter, grandson/granddaughter's partner needs a short break from caring, consider suggesting replacement care or respite care. More



information on this is available in the Headway booklet [Caring for someone with a brain injury](#).

## 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 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 wrong or right feelings when a relative has a brain injury.
- If you are a computer user, consider seeking support from Headway's online communities, such as [Headway HealthUnlocked](#). Online communities are used by people directly affected by brain injury or their families and friends, and are safe, secure spaces to share your thoughts or ask questions about brain injury. For more information, visit [www.headway.org.uk/supporting-you/online-communities](http://www.headway.org.uk/supporting-you/online-communities).
- Seek support from Headway services, such as the Headway helpline and your nearest group or branch. More information on these services is available at [www.headway.org.uk/supporting-you](http://www.headway.org.uk/supporting-you), or by contacting the free-phone, confidential helpline on 0808 800 2244 (Monday - Friday, 9am-5pm) or [helpline@headway.org.uk](mailto:helpline@headway.org.uk).
- If you are struggling to understand or cope with the changes that your grandson/granddaughter's brain injury has brought, try to find local support groups that can help you. Headway's groups and branches are available across the country to provide local support to brain injury survivors and their families. You can locate your closest group from the Headway website at [www.headway.org.uk](http://www.headway.org.uk).

## Practical considerations

- Be aware that a brain injury can, in some instances, leave a person unable to manage their own finances. They may therefore have a deputy appointed to manage finances on their behalf. It is important to be aware of this if you are giving a financial gift to your grandson/granddaughter, or if you are thinking of leaving a gift in your will.
- If you are considering getting a gift for your grandson/granddaughter, think about items that will help with any difficulties they have. For example, if they



have memory problems, consider technology that has built-in memory aids such as mobile phones with built-in alarms or note-taking systems. Or if your grandson/granddaughter struggles with using their computer, consider getting an adapted computer for them. 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 would be suitable.

- You may find that you need to provide more support to your own 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 you. As their parent, they may feel that 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, and it is hoped that the information in this factsheet 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.

**Headway relies on voluntary donations to enable us to continue to provide vital services to brain injury survivors and their families. There are a number of ways in which you can support our work, including:**

- **Leaving a gift in your will**
- **Taking part in or organising a fundraising activity**
- **Making a monthly or one-off donation**
- **Becoming a Friend of Headway**

To see how you can help us to improve life after brain injury for thousands of families across the UK, visit [www.headway.org.uk/donate](http://www.headway.org.uk/donate) or contact the fundraising team on 0115 924 0800.

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