Parents' guide to (adult) brain injury

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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 apprehensive for their son/ daughter's abilities and prospects.

This publication 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 brain injury, you can get 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 might 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 our publication *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 that you can feel close to them (for instance, helping with care). This can provide you with a sense of comfort and help you to feel involved in their care.
- Seek support from family members, close friend and Headway services. More information on how Headway can help is available at www.headway.org.uk/supporting-you or by contacting our helpline on 0808 800 2244 (Monday - Friday, 9am - 5pm).
- If your son/ daughter has children and you are helping out with childcare, refer to our publication *Supporting children when a parent has had a brain injury* for information and guidance.
- Learn more 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 our publication *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 regaining functional skills that have been affected by 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 our publication *Rehabilitation after brain injury*.

In the long-run

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 in the weeks and months that follow discharge, 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 into supported living accommodation or back in with their parents.

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 a brain injury survivor thinks, feels or behaves. It can also affect their skills and abilities. This section lists 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

Mobility issues

Sensory impairment

Visual problems

Epilepsy

Difficulties with speech

Hormonal imbalances

Weakness or paralysis on one/ both sides

Ataxia (irregular or uncontrolled movement)

Cognitive effects

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

Emotional and behavioural effects

Personality changes
Mood swings ('emotional lability')
Anxiety
Abusive or obscene language
Impulsiveness
Loss of confidence
Depression and sense of loss
Frustration and anger
Disinhibition
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 personal life goals, even if these are new ones.

Emotions such as sadness, grief, anxiety and anger are common to experience 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 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 (Monday - Friday, 9am-5pm) or helpline@headway.org.uk 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 especially distressing for parents.

There can be a sense of loss or grief felt by both the survivor and their parents, or others around them such as partners. While over time many people learn to adjust and accept the survivor's new life and sense of self, it is common for people to continue reflecting on the person they were before the injury. It is important for people to seek support with these feelings from close friends and/ or professionals, as struggling through these feelings alone can sometimes cause feelings of anxiety, depression and loneliness. 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 difficult to accept and adjust to.

In addition to the loss of support from one's son/ daughter, some parents feel that their own friends begin to drift away as a result of being less able to spend time socialising, especially if they have taken on caring roles. 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 - this might help to clear up any misunderstandings. You could also consider speaking to other families going through similar experiences, for instance, through your local Headway group or branch, or Headway's online communities. For more information on these, visit www.headway.org.uk/supporting-you.

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 was probably part of your normal routine. After a brain injury, you might find yourself supporting them with these tasks again. 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 a difficult 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, try not to take these outbursts personally and learn how to cope with such episodes - tips are available in our publication *Anger after brain injury*.

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 might have less time to spend with your friends or doing activities that you enjoy. Indeed, many carers report feeling socially isolated, and may not receive support or understanding from friends or other family members. The tips 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, it might be necessary to appoint a deputy for them, and you might consider taking on this role yourself, although you will still need to apply and this will be decided by the Court of Protection. 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 (2005). More information on what becoming a deputy involves and how to apply for deputyship is available in our publication *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, talk to family/ close friends about future arrangements, research what services your local council can offer, and consider writing a will. For advice on writing a will and information about leaving a gift in your will to Headway, visit www.headway.org.uk/donate/a-gift-in-your-will/.

Further information is available in our publication *Ageing carers*.

Tips for coping

Remember that brain injury affects people differently, so some of the tips in this section will be more relevant to yours and your son/ daughter's circumstances than others.

None of the tips in this section should replace clinical guidance.

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

- Read Headway's publications to learn more about the effects of brain injury and how you can help your son/ daughter to manage these on a daily basis. Headway's publications are all available to download free-of-charge at www.headway.org.uk/information-library, or by contact the helpline.

- Offer to help 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. This includes letting them take time to remember a word they want to use by themselves instead of finishing sentences off for them, or giving them time to think through the steps needed to complete an activity such as following a recipe.
- 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 everyday. This is as important for you as it is for them, as it means you are both able to spend some quiet time alone, even if this is just for a few minutes every 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 example encouraging your son/ daughter to talk through strategies to help with their memory.
- For general guidance and suggestions on tasks and exercises that you can do with your son/ daughter, refer to our publication *Redeveloping skills after brain injury*.

Seek support

- Seek support from relatives and close friends where possible. For example, 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, or offering to help with grocery shopping.
- If your son/ daughter needs support with activities of daily living 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.
- 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. More information on this is available in our publication *Carer's Allowance 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.
- Encourage your son/ daughter to speak to their GP about any further rehabilitation they may benefit from to help with the physical, cognitive, behavioural or emotional problems after 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, music 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 to ask how they are coping. Siblings of a brain injury survivor can sometimes be overlooked, despite the fact that they are likely to be affected by their sibling's injury as well. You could also consider directing siblings to our publication *Siblings' guide to brain injury*.

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 our publication *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.

We hope that the information in this publication 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.

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Headway
the brain injury association

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.

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