Headway
the brain injury association

Friends' guide to brain injury

If you are reading this publication, you may have a friend who has sustained a brain injury. Or perhaps you have heard about brain injury and wish to know more about it. This publication has been written to offer information to you about brain injury, how it might affect your friend and how you can help.

www.headway.org.uk
0808 800 2244

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Introduction

If you are reading this publication, you may have a friend who has sustained a brain injury. Or perhaps you have heard about brain injury and wish to know more about it.

Learning about brain injury is the first step towards helping someone affected by this 'hidden' disability. Many brain injury survivors feel that their lives would improve if their friends had a better understanding about what brain injury is, and their feelings and experiences through this life-changing occurrence.

This publication has been written to offer information to you about brain injury, how it might affect your friend and how you can help.

What is brain injury?

An acquired brain injury is any injury to the brain that has occurred since birth. There are many possible causes, including an accident (such as a road traffic accident, assault, fall) or illness (such as a tumour or a stroke).

In both the short and long-term, brain injury can cause changes in the way your friend thinks, feels and behaves, and can also affect their physical ability. Brain injury is often referred to as a 'hidden disability', as you may or may not be able to visibly see how your friend is affected, but this does not mean they are not experiencing effects that can cause challenges on a regular basis.

The early stages of your friend's brain injury

It can be a frightening and upsetting experience for anyone to have a friend in hospital with a brain injury. Your friend may be in for tests or surgery, or they might even have been in an accident. They might be in a coma or a reduced state of consciousness in the early days of their injury, which can be particularly distressing to witness. More information on this stage is available in our publication *Coma after brain injury*.

Even if your friend is conscious, they might be displaying unusual or uncharacteristic behaviour, known as post-traumatic amnesia. Although it can be difficult to see a friend in this state, be assured that it is a normal part of the recovery process. More information on it is available in our publication *Post-traumatic amnesia*.

You will naturally have many questions about your friend's condition, especially if this is the first time someone you know has been affected by brain injury.

However, it can be very difficult to predict the outcome of brain injury, so hospital staff looking after your friend may not be able to give you or your friend's family much information at this stage.

These experiences might leave you feeling concerned, confused and helpless, especially if you are unable to visit your friend in hospital. Here are some suggestions of things you can do that might help in the meantime.

- Refer to our publication *Hospital treatment and early recovery after brain injury* for general information about what might happen while your friend is in hospital. Encourage your friend's family to read this publication if they need information or guidance as well.

- If appropriate, help your friend's family by offering to do practical jobs such as shopping, childcare or researching where they can get support from.

- When visiting your friend, try not to overwhelm them with too much information or engage them in lengthy discussions, as they may struggle with fatigue or processing information.

- Consider creating a scrap book for your friend or using social media to share well-wishes from other mutual friends. This can not only give yourself and other friends an opportunity to share your thoughts and feelings, but can help to make your friend feel well supported.

- Your friend might be in hospital for days, weeks or even months after the initial injury and this length of time might concern you. Be patient, and remember that your ongoing support can have a positive impact on their recovery.

- Ask your friend if they would like you to update other friends about their recovery so that they do not have to repeat the same information when other friends ask after them.

The long-term impact of your friend's brain injury

When your friend is discharged from hospital and returns home, you might think this means that they have recovered from their injury and will soon be 'back to normal'. However, for many survivors, the emotional, cognitive and behavioural effects only become noticeable once they have returned home. Some survivors can, of course, continue to recover even weeks or months after the initial injury, although it is common for them to experience some effects in the early days.

This can be a frightening, confusing and frustrating time for your friend as they attempt to make sense of and adjust to their changed life. They might be unable to drive or return to work or education, and seemingly simple tasks such as grocery shopping or travelling can become major challenges. Rehabilitation might help your friend to regain some of the skills they struggle with over time, but even so, some effects can be ongoing.

Visit our website for more information on the common effects of brain injury.

The combination of these effects, and the practical impact they can have, can cause many brain injury survivors to feel like a 'new person' after their injury. For many survivors, this change can cause feelings of grief for their old self or the life they had before.

You may also be upset if your friend has changed, and you might deeply miss the person they were. However, try to realise that you are grieving together and that it is possible to move forward supporting one another and creating new memories.

Remember that while some effects continue for weeks, months or even years after the initial injury, some of them can get better

over time. The first few weeks or months may therefore be difficult, but things might gradually improve.

Continuing support and care can help your friend to feel more positive about themselves and their circumstances, which might have a positive impact on their overall recovery and general wellbeing. Do therefore try to stay in touch and support them, even if this is difficult at first.

Tips for supporting your friend

Learn about brain injury

- Read about the effects of brain injury and speak to your friend about which effects they personally experience. Our publications offer information on the effects of brain injury and are available to download for free at www.headway.org.uk.

- Remember that brain injury effects can fluctuate on a daily basis, so while your friend may appear to be well and functioning on one day, they might struggle the next day.

- Learn about different coping strategies to help your friend with managing the effects of their injury. For instance, if your friend has difficulties with managing their anger, refer to our publication *Anger after brain injury*.

Encourage your friend to get support

- Encourage your friend to contact their nearest Headway group or branch for support in their local area, or research this yourself so that you can provide them with helpful information. Your friend can also contact the Headway helpline on 0808 800 2244 (Monday - Friday, 9am-5pm) or

helpline@headway.org.uk for emotional support or information.

- If you suspect that your friend is feeling depressed, gently encourage them to talk about how they are feeling and to seek support, either from yourself, other friends or professional services. Information on the signs of depression and how to help are available in our publication *Depression after brain injury*.

- If your friend needs support with activities such as washing and dressing, and no existing provision is in place for this, encourage them to contact their local adult social care team. Information about the services that social care teams offer, and the process of making a referral, are available on local council websites.

- If your friend is experiencing ongoing effects of their injury that are affecting their quality of life, encouraging them to seek support from their GP and/ or get referrals to relevant professionals.

Look out for your friend

- Don't assume that just because your friend appears to be coping or does not take the initiative to contact you, they do not need help. Rather, ask after them and offer to help out where needed. At the same time, respect your friend's independence and do not assume that they cannot do things by themselves, as many survivors learn ways of adapting to their injury over time.

- Your friend may not be aware of some of the effects of their injury. This is known as lacking insight, and more information is available in our publication *Insight and awareness after*

brain injury.

- If appropriate, ask rehabilitation staff involved in your friend's rehabilitation whether there are any activities such as cognitive exercises that you can help your friend with.

Offer practical support

- Consider offering support with childcare if your friend has children, if this is appropriate.

- Ask your friend if they need any assistance with tasks such as grocery shopping, and if so, offer to pick up items while out doing your own shopping.

- If your friend is no longer able to drive or safely use public transport, offer to drive them to places such as outings that you are both attending, or to appointments.

- Offer to occasionally bring your friend healthy meals if they struggle with cooking for themselves. If your friend has problems with their taste or smell, consider using a variety of colours and textures instead. More suggestions are available in our publication *Taste and smell problems after brain injury*.

- Try to offer assistance with any forms your friend has to fill in, for instance if they are applying for welfare benefits. Such forms can often be lengthy and complicated, and may require information that your friend struggles to remember or find the correct words for.

- When buying gifts for your friend, consider selecting practical things that can help them on a regular basis. For example, if your friend has memory problems, consider getting them a journal or personal organiser.

Offering support when out and about

- Fatigue is a very common effect of brain injury, and can be a particular issue during or after outings. Try to keep outings short, and encourage your friend to rest beforehand and afterwards. Do consider that for many brain injury survivors, even a considerably short outing can cause them to experience fatigue the next day.

- If your friend struggles in busy, noisy environments, consider meeting with them somewhere quieter or visiting one another's house.

- Alcohol can worsen some of the effects of brain injury. While you cannot tell your friend whether or not they can drink, do remind them that alcohol can have a negative effect, and consider going alcohol-free yourself to support your friend.

- Ask your friend whether they would like you to explain that they have a brain injury to others while you are out together. This can make social situations easier, as others may be more understanding of their behaviour.

- Encourage your friend to use their Headway Brain Injury Identity Card when they are out. More information on the card is available at www.headway.org.uk/idcard.

- Try to set a recurring day and time for activities that you do together, as this can be helpful if your friend has memory problems or difficulties with organising and planning. If your friend has memory problems, ask if they would like you to send reminders the day before, and an hour before you are due to be seeing them.

- If your friend is unable to safely do activities that you both enjoyed before their injury, or they are no longer interested in those activities, try to find new or modified things that are safe and enjoyable. Remember that there are organisations that offer disability friendly sports, outdoor activities or holidays, so explore these options rather than excluding your friend from group outings.

What not to say to your friend

There are some things that people regularly say to brain injury survivors, which, though said with good intention, can be perceived by the survivor as being unhelpful and sometimes frustrating. The following lines are some examples of this that can be helpful to bear in mind while with your friend.

"I know what you mean, I have a terrible memory too."

An injury to the brain can prevent memories from being stored/retrieved. This is very different to the day-to-day forgetfulness that everyone experiences on occasion, and so should not be compared.

"But you don't look disabled."

The cognitive, emotional and behavioural effects of brain injury can still be present long after any physical injuries have healed. Therefore, just because the effects of the injury are not visible, this does not mean that they are not there.

"Move on and stop dwelling on what happened."

The effects of a brain injury can be life-changing and can last for months, years or even a lifetime. A person can't simply decide to 'get better' and move on.

"You should be back to normal by now."

No two brain injuries are alike, and no two journeys to recovery should ever be compared.

"You're tired? At your age?"

Fatigue is a regular and pathological tiredness. It is very different to the tiredness you might feel after a busy day. Tasks that many of us take for granted can become much more difficult when a survivor experiences fatigue.

"It's all in your mind."

The effects of brain injury experienced by a brain injury survivor are not purely psychological and should not be treated as such, even if they are not visible.

"Chin up - there's always someone worse off."

When trying to adapt to an entirely new life after brain injury, it doesn't always help to know that others may be dealing with worse, as defined by someone who doesn't understand what they're going through.

"Are you sure you should be doing that?"

An essential part of the rehabilitation process is relearning lost skills by pushing oneself to do challenging tasks. Although often said by people wanting to help, having one's ability judged by someone else can be frustrating.

"I know someone who had a brain injury and they're fine now."

No two brain injuries are the same. While it can be a motivation to hear of other people making good progress, it certainly isn't helpful to be judged for not recovering as quickly as them.

"But you were able to do that yesterday.."

Remember that the effects of brain injury can fluctuate on a regular basis, so while your friend might be able to do certain tasks on one day, they might struggle with these the next day.

Conclusion

We hope that the information in this publication has helped you to understand what your friend is going through after experiencing a brain injury, and how you can help them. Remember that friends form an important source of support for anyone going through any sort of difficult time, and your continuing support and understanding can have a positive impact on your friend's overall recovery.

We hope that this has been a helpful resource. Please consider sharing your feedback with us by scanning the QR code or by visiting our publication feedback survey https://uk.surveymonkey.com/r/hwpublications.

Learn more and support our work at www.headway.org.uk/get-involved.

This information was last reviewed in 2017.

We're here to listen.

If you need support, or have a question about brain injury, contact our free nurse-led helpline:

0808 800 2244
helpline@headway.org.uk

0115 924 0800 | enquiries@headway.org.uk
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