Partners' 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.

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Introduction

The relationship between a couple is often based on shared interests, values, memories and goals for the future. Couples often provide companionship, affection and care to one another, and are usually a source of support in times of hardship, such as when a brain injury occurs.

Partners can be particularly affected when a brain injury occurs, as it can be very upsetting and frightening to have a loved one in hospital. In addition to this, they often have a good understanding of the survivor's pre-injury personality, habits and emotions, and may therefore be more sensitive to changes in the survivor afterwards. The injury can also cause many practical changes to the couple's life, which can in turn affect the relationship itself.

This publication has been written for the partner of a brain injury survivor. It contains information on how brain injury might affect relationships and offers tips that might be helpful for some couples. Do remember that brain injury affects people differently, so while some of the information might be useful to you, other parts might not be relevant to your relationship.

The early days of injury

In the early days, your partner might be in a coma or a reduced state of consciousness. This can be a very upsetting and concerning time, especially as hospital staff might be unable to give you answers to questions that you have at this stage. For general information about these stages, see our publication *Coma and reduced awareness states*.

Even if your partner is conscious, they might be initially displaying unusual or uncharacteristic behaviour, known as post-traumatic amnesia. Although it can be very distressing to see them 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*.

It is normal at this stage to feel sadness, fear and grief, although you might also be relieved if, for instance, your partner has survived a catastrophic injury. There may be anxiety around practical arrangements, such as loss of income while your partner is unable to work or making arrangements to visit your partner in hospital. 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.

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.

You might find that you are having to take on additional practical responsibilities while your partner is in hospital, such as managing bills or looking after children on your own. This can be a very stressful and difficult time, especially while also dealing with the emotional impact on your partner's injury. Where possible, seek emotional and practical support from friends, family and Headway services during this time.

Here are some tips to help you cope during this stage:

- Refer to our publication *Hospital treatment and early recovery after brain injury* for general information and advice on this stage, including how Headway can help through this time.
- Ask hospital staff if you can be involved in meetings about your partner so that you are kept up-to-date about their treatment and the next stages of their care.
- Ask nursing staff whether you can assist with caring for your partner. This can help you to feel close to them, especially if they are in a coma or a reduced state of consciousness.
- If you have children, consider how much information will be appropriate to share with them about your partner's injury. More information and guidance on this is available in our publication *Supporting children when a parent has had a brain injury*.
- Provide your partner's friends and your mutual friends with updates, for instance through social media or Headway's website *I'm Calling About Chris* (www.callingabout.org.uk). Keeping friends informed and involved can help to ensure that your partner is still a part of their social network, which can be helpful to them in the long-run.
- Don't forget to look after yourself as much as you can during this time. You will likely want to spend as much time beside your partner as possible, but it is important for you to take breaks, rest and eat well. Remember that your partner will need to get plenty of rest during this stage as well.
- When spending time with your partner, if they are conscious, try not to overwhelm them with information or questions, as they might struggle with fatigue, their memory or processing information.
- Your partner may undergo a period of rehabilitation. Consider asking staff involved in their rehabilitation if there is any way that you can get involved, for example by helping your partner with activities and exercises outside of therapy sessions. More information on rehabilitation is available in our publication *Rehabilitation after brain injury*.

In the long-run

It is often assumed that once a brain injury survivor is out of hospital, they will be 'back to normal' in just a matter of time. Unfortunately, it is common for the effects of brain injury to become most noticeable and problematic once the survivor is back home, although some survivors can continue to recover even weeks or months after being discharged from hospital.

You will likely notice the effects of brain injury becoming more noticeable over time. Indeed, 'hidden' effects of brain injury, such as emotional and cognitive effects might be more apparent to you than to other people who spend less time with your partner.

Adjusting to changes in life following a brain injury can be difficult for both the survivor and their partner. Partners are often given little or no formal support, despite often taking on caring responsibilities. Feelings of sadness, longing for the past and isolation are common experiences. Acceptance for the new way of life does, however, develop over time for many, especially if the survivor continues to recover or learn coping strategies to regain their independence. In fact, some relationships strengthen over time as the couple learns new ways of managing the effects of the injury and their relationship.

Headway's campaign *You, me and brain injury* describes some of the changes reported in relationships following brain injury, including the challenges and strengthening of some couple relationships after brain injury. For more information, visit www.headway.org.uk/news-and-campaigns/campaigns/you-me-and-brain-injury.

Impact of brain injury on couple's relationship

Brain injury can cause a range of physical, emotional, cognitive and behavioural effects that can change the way the brain injury survivor thinks, feels or behaves. It can also affect their skills and abilities. Such effects experienced by your partner can have an impact on your relationship. Below are some of the common ways in which this can happen.

Changes in communication

Your partner might have problems with word-finding, understanding information or producing speech. They might also struggle with understanding and using non-verbal communication such as body language and facial expressions.

Day-to-day discussions can become difficult, and there may be frequent misunderstandings. It might take your partner more time and effort to make themselves understood. They might also struggle with expressing romantic feelings.

Such communication problems can be difficult for both of you, and you may find yourselves getting frustrated or communicating less over time. Learning ways in which to cope with communication difficulties can help, especially as communication is an important part of relationships. Refer to our publication *Communication problems after brain injury* for further information and guidance.

Changes in personality

Many people report feeling like a ‘new person’ after their brain injury. The effects of brain injury can cause an overall change in the brain injury survivor’s sense of self or their personality, which is often noticed by the partner as well. Sometimes, it might be the partner that notices this more, and the survivor may be unaware of the changes - this is known as lacking insight. More information on this is available in our publication *Insight and awareness issues after brain injury*.

Changes in personality can cause difficulties in a relationship. You may feel that you are no longer in a relationship with the person you initially chose to be with. Some survivors might also have changed feelings towards their partner.

Going through a catastrophic life event such as a brain injury can be incredibly difficult for anyone. Your partner’s personality might be different due to the recent experiences they have had, and it might take time for them to process everything that they have been through and overcome any trauma associated with it.

Changes in intimacy

Intimacy can be described as an emotional, physical and psychological closeness between people that is often accompanies by romantic feelings. It provides security and satisfaction for many couples. It can be sexual, but not always as intimacy can also refer to acts such as hand-holding, kissing and holding one another.

A brain injury can affect the intimacy between a couple in a number of ways. More information on this is available in our publication *Sex and sexuality after brain injury*.

Changes in behaviour

Changes in behaviour after brain injury are common, especially following an injury to part of the brain called the frontal lobe. Behaviour can become uninhibited and socially inappropriate, such as swearing or making inappropriate comments in public. This might cause you to feel embarrassment, frustrated or saddened.

Your partner might also make sexually inappropriate remarks or engage in sexually inappropriate behaviour, which can be particularly distressing for you.

A lack of motivation might affect your partner's ability to engage in activities. As a result, your social life might be affected and you might, in turn, feel depressed, isolated or frustrated.

Changes in cognitive ability

Cognition refers to our ability to learn, think, remember and process information. These skills are commonly affected after brain injury. Memory problems are particularly common, and can affect relationships if, for instance, your partner cannot remember significant dates such as your anniversary or birthday. They might also struggle with remembering day-to-day plans such as appointments and planned outings.

You might find yourself having to repeat things several times, offer reminders and be responsible for planning and organising things far more than you did before the injury.

Information and guidance on memory is available in our publication *Memory problems after brain injury*.

Problems with setting goals, multi-tasking, decision making and problem solving are collectively known as executive dysfunction. These can also cause practical and emotional challenges. More information and guidance on this is available in our publication *Executive dysfunction after brain injury*.

Practical changes

Your partner might be unable to work or drive after brain. You will likely need to adjust aspects of your life to accommodate for these changes. There might also be a change in the type or frequency of activities that you do together. For example, fatigue might make it harder for your partner to socialise, or there might be certain places they are no longer able to comfortably visit due to noise levels.

If you previously relied on a joint income and your partner is no longer able to work, you might need to consider applying for welfare benefits. More guidance on this is available in the benefits publications on our website at www.headway.org.uk/information-library.

Role changes

Practical changes can cause yours and your partner's roles to change. For instance, you might need to take on new responsibilities that your partner previously did, such as managing household finances. This can be stressful, as you will likely be having to manage these new responsibilities alongside other aspects of your life. However, it will probably also be difficult for your partner to adjust to this change, and their self-esteem might be affected if they are no longer able to do tasks that they did before their injury.

Many partners report feeling less like a romantic partner and more like a carer if they are required to support the survivor with aspects of daily living such as washing and dressing, which can also be a difficult change in role to accept and adjust to.

Changes in capacity

A brain injury can impair a person's ability to make decisions for themselves. If a person lacks capacity to make decisions, you may take on the role of deputy so that you can make decisions on their behalf in their best interests. Applying for deputyship, becoming a deputy or making alternative arrangements can be a lengthy, complex and stressful process. More information on this is available in our publication *Mental capacity: supporting decision making after brain injury*.

Tips for coping

The way a couple manages their relationship will depend on the nature of the relationship, personality types and the effects of the brain injury. Different things will therefore work for different couples. The following general suggestions might be helpful ideas to consider to help with managing your relationship.

Learn about brain injury

- Learn about the effects of brain injury, and talk to your partner about which effects they personally experience. Understanding this can allow you to offer the most appropriate support and find strategies to manage the effects together. Refer to Headway's publications for information on many of the effects of brain injury, available at www.headway.org.uk/information-library.
- Ask your partner how they feel about you sharing information about their injury with mutual friends. With their agreement, you could also consider sharing our publication *Friends' guide to brain injury.*
- Remember that the effects of brain injury can fluctuate on a regular basis, for instance fatigue can be worse on some days than others. Try to recognise patterns, take time to ask how your partner is feeling each day and try to plan activities around this accordingly.

Communicate with one another

- Let your partner know how you are feeling, and gently encourage them to share their feelings with you too. Do not assume that your partner will know how you are feeling without telling them, especially if they struggle with interpreting body language and/ or facial expressions.

- Consider asking your partner to express their feelings creatively, for instance through art, music or creative writing. This can be therapeutic for many people, and can also make it easier for some survivors to share feelings that they would otherwise struggle with expressing.
- If your partner displays inappropriate behaviour, tell them gently but firmly to stop. This might be difficult, but it can help your partner to re-learn important social skills. Encourage other members of the family and mutual friends to do the same, and keep messages consistent.
- Use clear and direct language to help your partner with understanding information if this is something that they struggle with.
- Be patient with your partner; give them time to finish sentences and express themselves, even if they are talking slowly or struggling to think of a word.
- Do not pretend to have understood your partner if you have not. Instead, repeat back to them information that you have understood so far and ask them to repeat themselves.

Practical arrangements

- Offer to help your partner with completing forms and attending assessments or appointments with them. Input from those who know the survivor well can often be vital, especially if the survivor lacks insight or has memory problems.
- Where possible, try to balance responsibilities as a couple. Take on responsibilities that your partner is no longer able to do, and ask them to complete tasks that they can do safely. For instance, if your partner cannot remember the steps involved in cooking a meal, ask them to chop/ prepare ingredients while you do the cooking itself.
- Keep a clearly written reminder and record of planned outings or appointments, for example keeping a joint diary that the survivor checks

everyday or a clearly visible calendar.

- Contact your local adult social care team if your partner needs support with activities of daily living (washing, dressing, etc) and you are unable to help.
- Don't rush to do everything for your partner; let them try things for themselves if they can do them safely. This is an important part of rehabilitation, as they will need to challenge themselves at times to relearn skills.

Be considerate to one another

- Be considerate of the fact that this will probably be a stressful time for both of you. Try to be forgiving of behaviour that you know is a result of the brain injury.
- Show appreciation for one another in small ways, such as saying thank you, writing notes or letters or buying small gifts for one another
- Respect your partner's need for personal space.
- Arrange a date night or plan a special activity to do together. Choose something that accommodates for your partner's needs. For example, if they struggle with loud noises and bright lights, they might feel uncomfortable going to the cinema and may prefer a movie night at home instead.
- Be considerate of the anniversary of your partner's injury. This will likely be an emotional time for both of you. Be sensitive to any changes in your partner around this time, and encourage them to speak to you or get emotional support if they need it.

Do enjoyable and meaningful activities together

- Having a brain injury does not stop someone from going on holiday. Consider disability friendly facilities and holiday packages that might be suitable for your partner's needs. More information and tips are available in our publication *Holidays and travel after brain injury*.

- Celebrate achievements in your partner's recovery. You might wish to do this by creating a journal or scrapbook in which you record their progress over time.
- Help your partner to identify new hobbies or interests that you can do together, or encourage them to find things they can do by themselves. They could even consider volunteering for an organisation or a cause they are interested in or passionate about, which can be a very rewarding and fulfilling experience. More information on this is available in our publication *Volunteering after brain injury*.

Get support

- Encourage your partner to speak to their GP if they are experiencing ongoing effects of their injury.
- Find out how Headway can help you by visiting the 'Supporting you' section of our website (www.headway.org.uk/supporting-you) or by contacting the helpline on 0808 800 2244 (Monday - Friday, 9am-5pm) or helpline@headway.org.uk.
- If you feel that your relationship is struggling, consider getting professional support, for instance from a couple's therapist. More information on this is available in our publication *Relationships after brain injury*.

Look after yourself

- Remember that it is important for you to occasionally take time to relax by yourself. Even a few quiet moments to yourself every day can help.
- Don't forget that Headway's helpline and groups and branches are available to support partners as well as brain injury survivors themselves.
- Allow yourself to be honest about your feelings and work through these at your own pace. Consider getting professional support if you are struggling with your emotions, for instance through counselling.
- If you are struggling with the role of caring for your partner, get advice and

support from carer organisations. You could also explore the option of arranging respite care. More information on these issues is available in our publication *Caring for someone with a brain injury*.

Conclusion

Relationships between couples can often be impacted by brain injury. Sometimes relationships can become strained, but with understanding, support and the right techniques in place, relationships can continue to flourish after brain injury and may even grow stronger over time. Unfortunately break ups can happen in any relationship, but we hope that the information in this publication has helped you as a partner to cope with 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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