



Brain injury: A guide for partners

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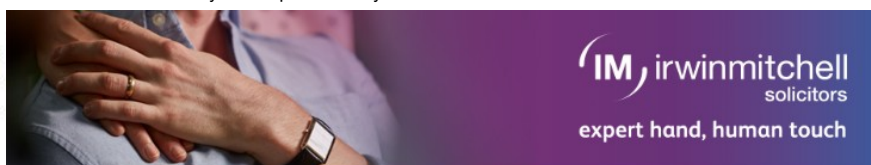
Introduction

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

Partners can be particularly affected if their spouse, boyfriend or girlfriend sustains a brain injury, 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 personality, habits and emotions of their partner before the injury and are therefore often aware of how their

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improving life after brain injury



partner has changed afterwards. The injury can also cause many practical changes to the couple's life, which can have an overall effect on the relationship itself.

This factsheet has been written for the partner of a brain injury survivor. It contains information on how brain injury can 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 following information might be useful to you, other parts might not be relevant to yours and your partner's situation.

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, refer to the factsheet [Coma and reduced awareness states](#).

Even if your partner is conscious, they might initially be 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 the factsheet [Post-traumatic amnesia](#).

In any case, having a partner sustain a brain injury can cause feelings such as sadness, fear and grief, although you might also be relieved if, for instance, your partner has survived an accident. 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. Your feelings might also change as the impact of your partner's injury becomes more apparent.

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. It can be a very stressful experience having to manage such things while also dealing with the emotional impact of your partner's injury. Where possible, seek emotional and practical support from friends, family and Headway services during this time.

Below are some tips that can help you to cope with the early stage of your partner's injury.

- Refer to the booklet [Hospital treatment and early recovery after brain injury](#) for general information about this stage.
- Ask hospital staff if you can be involved in meetings about your partner's care 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 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 the booklet [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. Keeping friends informed and involved can help to ensure that your partner is still a part of their social network, which can be helpful in the long-run.
- Seek support from family, close friends and Headway services. More information on how Headway can help, including details of our helpline, Emergency Fund and Acute Trauma Support Nurses is available at www.headway.org.uk/supporting-you.
- Don't forget to look after yourself during this time. This might be difficult, as you will likely be preoccupied with thoughts of your partner and will want to spend as much time beside them as possible, but it is important for you to take breaks from your partner's bedside and rest when possible.
- 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.
- If your partner undergoes a period of rehabilitation, consider asking rehabilitation staff if you can get involved, for instance, by helping your partner with activities and exercises outside of therapy sessions. More information about this is available in the booklet [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 their usual self in just a matter of time. Unfortunately, it is common for the effects of the injury to become most apparent 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 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 who spend less time with your partner. Hope for the future can sometimes give way to sadness and concern as the effects become more noticeable and start to affect a couple's practical and social life.

Adjusting to changes in life following a brain injury can be difficult for both the survivor and their partner. In addition to this, partners are often left with little or no support, despite often having to take on caring responsibilities. These changes can typically cause feelings of isolation, longing for the past, and sadness. Acceptance for the new way of life can, however, set in over time, especially if the survivor continues to recover or learns coping strategies to regain their independence. Indeed, some relationships strengthen over time as the couple learn new ways of managing the effects of the injury and their relationship.

How the effects of brain injury can affect a 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, comprehension or speech production and 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, as it might take them more time and effort to make themselves understood. They might also struggle with expressing romantic feelings. Such communication problems can be frustrating and upsetting for both of you, and you might communicate with one another less over time.

More information on this issue is available in the booklet [Coping with communication problems after brain injury](#).

Changes in personality

Many brain injury survivors report feeling like a new person after their injury. Indeed, the emotional, cognitive and behavioural effects of brain injury can cause an overall change in their personality, which is often also noticed by their partner. Sometimes, however, a survivor might be unaware of how their personality has changed or how the injury has affected them. This is known as lack of insight, and can be a particular challenge for partners to deal with. More information on this is available in the factsheet [Lack of insight after brain injury](#).



Either way, a change 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. Sadly, some partners even go so far as to describe the brain injury survivor as becoming a stranger. Some survivors might also experience emotional, psychological or cognitive effects that alter their own feelings towards their partner.

Changes in intimacy

Intimacy can be described as an emotional, physical and psychological closeness between two people that is often accompanied by romantic feelings. It provides security and satisfaction for many couples. This can either be sexual, although not always. Intimacy can refer to non-sexual acts as well, such as hand-holding, caressing, kissing and holding one another.

Intimacy between a couple can be affected if, for instance, the brain injury survivor has a lack of insight or anger problems. Detailed information on how brain injury can affect intimacy is available in the booklet *Sex and sexuality after brain injury*.

Changes in behaviour

Changes in behaviour after brain injury are common, especially following an injury to the area of the brain known as 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 embarrassed, frustrated or saddened.

Your partner might also make sexually inappropriate remarks or engage in sexually inappropriate behaviour, which can be particularly upsetting or embarrassing 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

Cognitive (thinking) skills are commonly affected after brain injury. Memory problems are particularly common, and can affect relationships if, for instance, your partner struggles with remembering significant key dates (such as anniversaries or birthdays) or important memories (such as your wedding day or first date). They might also struggle with remembering things on a day-to-day basis, such as appointments and planned outings.

You might find yourself having to repeat things several times, and this can get tiring. You might also feel upset if your partner is not able to remember important and sentimental memories. More information about this is available in the booklet [Memory problems after brain injury](#).



Problems with attention, multi-tasking and decision making are collectively known as executive dysfunction, and can also cause practical and emotional challenges. More information on this is available in the factsheet [Executive dysfunction after brain injury](#).

Practical changes

Your partner might be unable to work or drive after their injury. As a result, you may need to readjust aspects of your life to accommodate for such changes. There might also be a change in the type of activities, or pace of activities that you can partake in together. For instance, fatigue might make it harder for your partner to socialise and spend late evenings out, or there may be certain places that they are no longer able to visit if they now struggle in noisy environments.

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 information on this is available in the booklet [A guide to welfare benefits](#).

Role changes

Practical changes can cause yours and your partner's roles to change. For instance, you may 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 along other aspects of your life. However, it will also probably 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.

You might also have taken on a caring role if you are supporting your partner with day-to-day tasks. Adjusting to the roles of both partner and carer can be challenging, especially if you are having to support your partner with things such as washing and dressing.

Changes in capacity

Some survivors lose their ability to make informed decisions themselves about serious or legal issues, known as lacking mental capacity. You may take on the role of deputy, through which you become legally responsible for making decisions on their behalf. 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 the booklet [Mental capacity: supporting decision making after brain injury](#).

Tips for managing couple relationships after brain injury

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. 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 sharing information about their injury with mutual friends. With their permission, you could even consider sharing the factsheet *Brain injury: a guide for friends* with your mutual friends.
- Remember that the effects of brain injury can fluctuate on a regular basis. For instance, your partner's fatigue might be worse on some days than others. Take time to ask how your partner is feeling each day, and try to plan activities around this accordingly.

Communicate with one another

- Communicate openly with one another, and be honest about your thoughts and feelings. Do not assume that your partner will know how you are feeling without you telling them. Similarly, do not assume that your partner is coping if they do not talk about their injury.
- Consider asking your partner to express their feelings creatively, for instance through art 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.
- Consider writing letters to one another, as this allows you both to take time with finding the right words to express yourselves.
- Tell your partner gently but firmly if their behaviour is inappropriate. This might be difficult, but it can help your partner with re-learning social skills. Encourage other members of the family and mutual friends to do the same, and keep messages consistent.
- If your partner struggles with processing information or takes things very literally, use clear and direct language so that they do not get confused.



Practical arrangements

- Assist your partner with filling out forms, and attend appointments and assessments 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 your 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. Or consider taking turns with tasks that your partner is able to do, but in a reduced capacity.
- Keep a written reminder and record of planned outings or appointments in a visible place for your partner to refer to if they have memory problems.
- Consider contacting your local adult social care team if you feel your partner needs support with activities of daily living that you are unable to assist with. Information about the services that social care teams offer, and the process of making a referral, are available on local council websites.
- Allow your partner to try things themselves, and don't feel that you need to rush to do everything for them. 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 mindful of the fact that this will probably be a stressful time for both yourself and your partner, so try to make allowances for 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.
- Encourage your partner to occasionally take time to themselves and allow you to do the same, and respect one another's need for personal space.
- Arrange a date night or plan a special activity to do together occasionally. If you have children or other dependents, try to make arrangements in advance for them to be looked after so that you are not disturbed.

Do enjoyable and meaningful activities together

- Book a holiday away together. Holidays are still possible for many brain injury



survivors and there are disability friendly facilities and holiday packages that might be suitable depending on your partner's needs. More information and tips on going on holiday are available in the factsheet [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 that they can do by themselves. They could even consider volunteering for an organisation or a cause that they are interested in or passionate about, which can be a very rewarding and fulfilling experience. More information on this is available in the factsheet [Voluntary work after brain injury](#).

Seek support

- Encourage your partner to speak to their GP and/or request referrals to relevant professionals if they are experiencing ongoing effects of their injury.
- Contact the Headway helpline for information about brain injury or emotional support. The helpline is available on 0808 800 2244 (Monday - Friday, 9am-5pm) or helpline@headway.org.uk.
- If you feel that your relationship is struggling, consider seeking professional support, for instance from a Couple's Therapist. More information on this is available in the Headway booklet *Relationships after brain injury*.

Be intimate with one another

- Intimate acts provide physical and emotional comfort that can often deepen the connection between people. Try to make a conscious effort to regularly be intimate with one another, even in small ways such as holding hands or stroking one another. More tips about encouraging intimacy are available in the booklet *Sex and sexuality 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 groups and branches offer support to partners and



carers of a brain injury survivor as well as survivors themselves. For more information, visit www.headway.org.uk/supporting-you.

- Allow yourself to be honest about your feelings and work through these at your own pace. Consider seeking professional support, for instance through counselling, if you are struggling with your emotions.
- If you are struggling with the role of caring for your partner, consider seeking support from carer support organisations. You could also explore the option of arranging respite care. More information about this is available in the booklet [Caring for someone with a brain injury](#).
- If you are struggling with your relationship, and you have exhausted all avenues of trying to make the relationship work, remember that break ups are, sadly, sometimes the only option left to a couple. Speak to your partner, family and close friends first. The Headway helpline or other relationship services can also offer a listening ear, but remember that ultimately the decision rests with yourself and your partner.

Conclusion

The relationship between a couple is unique and can be deeply affected in different ways by a brain injury. Sometimes relationships can become strained as a result of the impact of the effects of the injury. However, with understanding and support, relationships between couples can be successful.

It is hoped that the tips given in this factsheet have helped you to identify ways in which to manage your relationship. More information is available in the Headway booklets *Relationships after brain injury* and *Sex and sexuality after brain injury*, both of which are available from www.headway.org.uk/information-library.

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