



Waiting for rehabilitation after brain injury

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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. Thank you.

Introduction

After a discharge from hospital, many brain injury survivors require a period of rehabilitation to facilitate their recovery. This can either be as an inpatient, where they will reside within a brain injury rehabilitation unit for a period of time and receive therapy, or as an outpatient where rehabilitation will be received from a community-based team in their area.

Unfortunately, such services often have long waiting lists and it might be weeks or even months before the brain injury survivor is able to receive rehabilitation. For many survivors and family members, this can be a difficult and confusing time, and family members may wonder what they can do to help their relative in the meantime.

This factsheet has been written for family members of a brain injury survivor who is at home and on a waiting list to receive rehabilitation. It gives tips and information to help the family support their relative during this waiting period, and directs the reader to other useful and relevant Headway resources that can help during this time.

Tips while waiting for rehabilitation

Rehabilitation aims to improve the degree of recovery a person makes after brain injury. It is most effective when accessed within the first few days of being discharged from hospital rather than weeks or months afterwards. However, there is also potential for the brain to make some degree of natural recovery. The process underlying this is still not yet fully understood, but it is thought that some degree of re-organisation of the cells of the brain takes place in the hours, days and weeks after the injury. This may allow the brain injury survivor to make improvements even while they are at home waiting for rehabilitation.

During this period it is important to consider the following:

- Keep in touch with your relative's GP to ensure that the arrangement for rehabilitation is still on track.



- It is common for people to experience fatigue after brain injury, especially in the first few weeks. If your relative is feeling fatigued, let them rest and encourage them not to fight through it. More information on this is available in the Headway booklet *Managing fatigue after brain injury*.
- Minimise levels of stimulation in your relative's environment, such as loud noises or very bright lights.
- Encourage your relative to gradually increase their activities in the first few weeks rather than going straight back into the routine they had before their injury. This is especially important if your relative lacks insight into how their injury has affected them. More information on this is available in the Headway factsheet *Lack of insight after brain injury*.
- Remember that problems with managing anger are a common effect of brain injury. If the anger is being directed at you, try to stay calm and remind yourself that it isn't personal. For more information on this, see the Headway booklet *Managing anger after brain injury* and the Headway factsheets *Managing anger: tips for brain injury survivors* and *Managing anger: tips for families, friends and carers*.
- Your relative may be very tearful or upset, and they may have difficulty controlling their emotions. Gently reassure them that this should settle with time and encourage them to seek support from services such as their local Headway group or branch, or the Headway helpline on 0808 800 2244 or helpline@headway.org.uk.
- Memory problems are another common effect of brain injury. It may be necessary to remind your relative of things or to prompt them sometimes. If they have ongoing problems with their memory, the rehabilitation team should be able to help with introducing ways of coping with this. For more information and tips to try at home, see the Headway booklet *Memory problems after brain injury*.

You may wish to consider exploring the idea of a home activity programme. This involves creating a regular schedule for your relative that consists of activities around the home that they can enjoy and undertake safely. You can celebrate progress as they complete the activity, for instance each time they are able to make a cup of tea without needing to remind them where the teabags, milk and sugar are kept. More information about designing a home activity programme and other useful tips are available in the Headway booklet *Redeveloping skills after brain injury*.

The family's role in rehabilitation

Rehabilitation is not only carried out by the brain injury survivor and their rehabilitation team. Family members are often a key part of the rehabilitation process, as they provide important emotional and practical support to the brain injury survivor throughout the early



days and rehabilitation process. As a family member, it is important for you to remember that how you interact with your relative can be a help or a hindrance, depending on your own response to their behaviour.

For example, if your relative is getting angry and you respond by shouting back, this may reinforce the angry behaviour. If, on the other hand, you respond by being calm and managing the anger effectively, you will be encouraging appropriate behaviour and this will help with their recovery.

Learning about brain injury can be very useful not only for the brain injury survivor themselves but also family members and friends. Having an understanding of the effects that the brain injury survivor is currently experiencing, and may experience in the future, can help with devising coping strategies. It can be particularly useful to use the time you have while waiting for rehabilitation to educate yourself about brain injury. This might help your relative to understand their own injury, and also how rehabilitation can help with their recovery.

It can be a big responsibility to take on the role of caring for someone with a brain injury, especially if they have returned home without any rehabilitation. As a carer, you may choose to give up hours at work or find that you have less time to yourself.

If possible, consider making arrangements for other family members or friends to spend time with the brain injury survivor on a weekly basis. You could also find out whether social services can arrange for some support with caring, for instance through a support worker visiting, or look into local befriending schemes. This can allow you to take a short break from your caring role. It can also be recognised as 'therapy' time if the family member or friend has a particular routine of completing a specific activity with the brain injury survivor each time they visit. More information and tips for taking on a caring role is available in the Headway booklet *Caring for someone with a brain injury*.

Some Headway groups and branches are also able to offer respite care and peer-to-peer support to carers. More information on this is available below.

Sources of support in the meantime

Headway groups and branches

Headway operates a network of support groups and branches across the UK that can offer local support to brain injury survivors and their families. To locate your nearest Headway group or branch, visit www.headway.org.uk/supporting-you.

Headway helpline

The nurse-led Headway helpline is available to offer emotional support and information at



any stage of someone's brain injury. To contact the helpline, call 0808 800 2244 or email helpline@headway.org.uk.

Your relative's GP

Your relative may already have some level of support in place arranged by the hospital upon their discharge, for instance through the NHS continuing healthcare scheme. However, if there has been no provision of support and your relative feels that they need something in place while they are waiting for rehabilitation, encourage them to speak to their GP. It might help if you attend the appointment with them so that you can raise concerns that your relative may forget to mention or lack insight on. The GP might be able to refer your relative to local services in the area that can help in the meantime.

Private rehabilitation

In some instances it may be possible to arrange for private rehabilitation, for instance if your relative has a compensation claim underway, in which case they or you should discuss the option of private rehabilitation with the solicitor involved. Private rehabilitation is otherwise very expensive and should be explored properly first. The Headway helpline can offer information and direct you to organisations that offer private rehabilitation therapists. It might be possible to arrange for a brain injury case manager to facilitate access to private rehabilitation, but again these are often only accessible when there is a compensation claim underway.

Other practical support

If you or your relative requires support in the home or with daily aspects of living, consider contacting the local authority's adult social care team to arrange for a needs assessment. More information about this is available on the NHS website at www.nhs.uk/conditions/social-care-and-support-guide, or from your local authority's own website.

Your relative's changed circumstances may entitle them to various welfare benefits, for instance if they are no longer able to work. More information on this, including what benefits are available and how to apply for them, is available in the Headway booklet *A guide to welfare benefits after brain injury*.

You may also wish to speak to your local Headway group or branch to see whether they can offer you some practical support in the mean time.

Making a complaint about waiting for rehabilitation

If you feel that your relative's care has not been appropriately managed, or that being placed on a waiting list has been detrimental to your relative's recovery, you might wish to start off by raising concerns with your relative's GP. If you are still not satisfied, you could consider referring your complaint to an ombudsman or other equivalent service.



Information and guidance on how to make a complaint is available in the Headway factsheet *Making a complaint about health and social care services*.

Frequently Asked Questions

Will the fact that my relative has to wait for rehabilitation have a negative impact on their recovery?

This depends on a number of factors such as the length of the waiting list. A few weeks of waiting should not hinder your relative's recovery, in fact this can give them time to adjust to being at home and may help them to realise what their strengths and weaknesses are. You should be vigilant for any effects of your relative's brain injury that are a cause for concern. If you find that they are getting depressed, anxious or increasingly angry, you should encourage them to see their GP. If they have any seizures, they should go to their nearest Accident and Emergency unit. If they are experiencing regular headaches or difficulties with dizziness or balance, encourage them to ask their GP to refer them to a neurologist. If you are concerned about any symptoms that suddenly develop, ring NHS 111 or call for an ambulance. Specific guidance on symptoms to look out for and who to contact if you have concerns should be available in any information given to you by a discharge coordinator when your relative left the hospital.

I've heard that recovery after brain injury stops after a year. Is this true?

People do sometimes talk about there being a limited 'window' of recovery after brain injury, for example, that recovery ceases to take place beyond a year. However, this is now known not to be the case and people may actually continue to improve for a number of years after brain injury. Indeed, many people say that they never stop regaining the skills that they lost following their injury. Nevertheless, the greatest visible progress does occur in the first six months or so after the injury and improvement after this is often less obvious.

What if my relative hasn't got a referral to rehabilitation, but I think they need it?

If your relative has been discharged from hospital with no arrangement for rehabilitation and you have reason to believe that they would benefit from it, there are still options available. You and your relative are perfectly within your rights to actively seek rehabilitation services, even if you have been told that there are none available or needed.

The first thing to do is discuss the matter with your relative's GP and/or consultant. They may be able to provide a referral. You can also search for rehabilitation services yourself and contact them directly. Headway's Approved Provider directory gives details of rehabilitation units across the UK that have been accredited by Headway. For more information, visit www.headway.org.uk/supporting-you. More information and guidance on finding rehabilitation services is available in the Headway booklet *Rehabilitation after brain injury*.



the brain injury association

factsheet

To discuss any issues raised in this factsheet, or to find details of our local groups and branches, please contact the Headway helpline free of charge on 0808 800 2244 (Monday - Friday, 9am-5pm) or by email at helpline@headway.org.uk.

You can also find more information and contact details of groups and branches on our website at www.headway.org.uk/supporting-you.

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