

The family guide to brain injury



IN THIS GUIDE:

- Advice for leaving hospital
- Tips for managing the effects of a brain injury
- Where to get further information and support
- Ways to help children and teenagers adjust to a brain injury in the family
- Practical suggestions
- Ways to look after yourself

An Acquired Brain Injury is an injury to someone's brain that happens during their lifetime. It can be caused by a stroke, an infection, lack of oxygen or trauma, for example. Throughout the booklet, we use the phrase 'brain injury' to refer to an Acquired Brain Injury.

Please contact us in Headway on t: 1890 200 278 or 01 6040 800, e: info@headway.ie or w: headway.ie if you would like to give us feedback. We are also here if you need further information or support or if you would like any of the booklets in the Brain Injury Series that we mention throughout this guide.

Please note: we have done our best to provide information that is correct and up-to-date. However, we cannot be responsible for any errors or omissions. You shouldn't consider the information in this booklet as a substitute for getting advice from a doctor or other professional.

“What I'd say to other family members is that you are not alone. There is help out there and there is a way around every problem.”

Martha, Co Dublin

Booklet concept and content development: Brain Injury Information and Support Team, Headway Ireland.

Lead: Ruth Lunnon, Senior Information and Support Worker.
See headway.ie/information for further details.

Our sincere thanks to all the family members who shared their experiences and generously gave of their time to help create this guide.

**© Headway Ireland 2017. Next review due in 2019.
All rights reserved by Headway Ireland.**



Contents:

| | |
|---|----|
| Introduction..... | 1 |
| How to use this guide | 2 |
| Brain injury | 3 |
| The next steps..... | 4 |
| Leaving hospital | 4 |
| Options after hospital | 5 |
| Checklist for leaving hospital..... | 7 |
| The professional – who is who? | 9 |
| Back at home | 12 |
| Common things your family member may experience and what to do | 13 |
| Getting services and support..... | 14 |
| Coping with changes..... | 15 |
| Symptoms, medications, seizures and headaches..... | 15 |
| Changes in thinking, organising, communication and memory | 16 |
| Physical and sensory changes | 18 |
| Personality, behaviour and mood changes | 20 |
| Looking after your own well-being | 28 |
| Relationships and intimacy..... | 31 |
| Helping children and teenagers to adjust | 33 |
| Moving forward | 35 |
| Some final thoughts | 37 |
| Help and information | 38 |
| Index | 40 |

Introduction

When someone suffers a brain injury, it doesn't just happen to them, it happens to the whole family. If you are reading this guide, you are probably going through many experiences that you didn't expect or get a chance to plan for. Headway worked on this booklet with family members of people with a brain injury. We hope their experiences, and the up-to-date information we provide, will help support you and your family to find the best way to live after a brain injury.

Families like yours can face challenges that other people don't see. We give lots of advice on coping with 'hidden' difficulties (for example, personality changes) because families told us these were the hardest changes to adjust to. Taking care of yourself is as important as looking after the injured person and throughout the guide we suggest ways of doing that.

What the symbols mean:



Practical tips and information based on other family member's experiences and up-to-date knowledge.



Ways to take care of yourself.



Who to contact for information, services or support.



Key points of information.



Encouraging quotes from family members.



Suggestions of other booklets to read. They are available online or in print from Headway.

How to use this guide

The idea of this guide is to use sections of it as you need them, rather than reading it cover-to-cover. You can make it your own by writing in ideas and notes.



If you feel you don't need this guide now, keep it in case you need it later. If your family member is still in early recovery, you may find our **Hospital stage guide** useful - see headway.ie/information.

- To get an idea of what this Family Guide covers, start by quickly glancing through it. Use the **Index** at the back if you want to look up something specific.
- Mark any sections of the guide or tips that make sense to you. Try out the tips.
- Write in what worked or new ideas you want to try. There are some blank pages for notes in this guide. It might be handy to get a notebook also.
- If the same issues come up again, use the ideas that worked before or try new ones.
- Move on to new sections as you need them.
- This booklet may also be useful to friends and professionals. They can get extra copies from Headway or read it online at headway.ie/information.



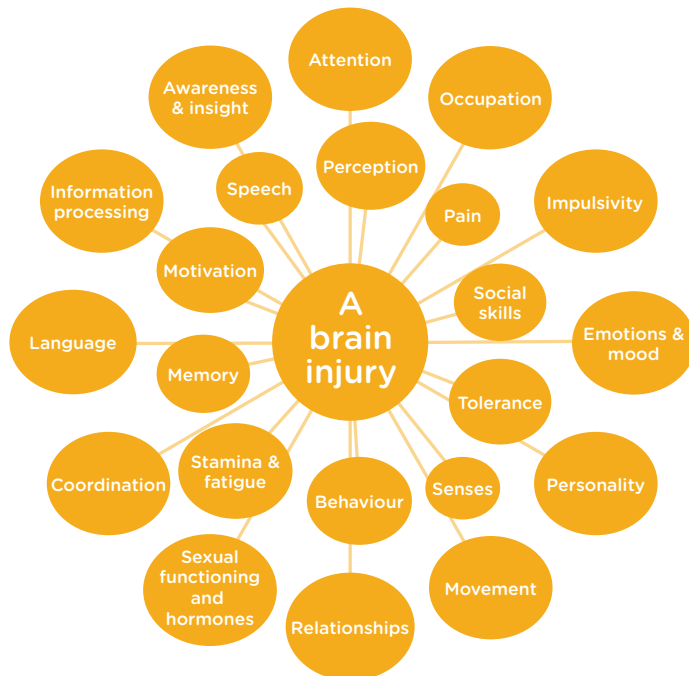
Bear in mind that not all of the issues in this guide will affect you, your family or the injured person.



Headway's Information and Support Team developed this guide. We will be happy to assist you to get the most out of it. If you have any questions or would like further advice, call us on 1890 200 278, 01 6040 800 or email helpline@headway.ie

Brain injury

There are many causes of a brain injury including stroke, lack of oxygen, infections, tumours, road accidents and falls. The injury may affect your relative in different ways – no two people are the same. Some effects can be long-lasting while others may improve over time.




We give suggestions for ways to adjust to many of these effects throughout this guide. If you, and the person with the injury, want further information or advice see our **Brain Injury Series** of booklets online or in print (including *The brain and brain injury*). In each section of this guide, we tell you which booklets are relevant.



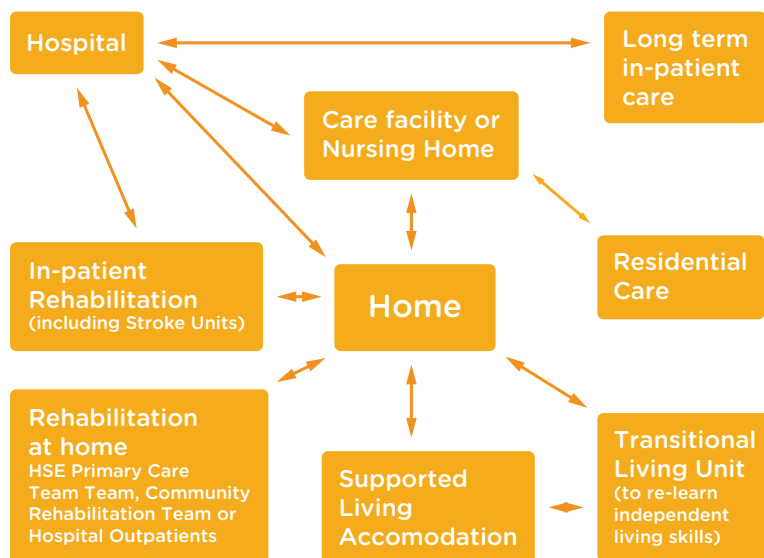
The next steps - leaving hospital

When your family member is close to being ready to leave hospital, a team of hospital staff will start planning what services they should receive next. The staff will discuss any decisions with you and your family member if they are well enough. This planning team is usually lead by the Hospital Social Worker who will link with the GP, the Public Health Nurse and other HSE Primary Care Team staff. See pages 9 and 10 for details of who is who.

Tips for communicating effectively with staff

- Bear in mind that, as a close family member, you have a valuable role to play in your relative's recovery and in decisions about their rehabilitation because you know what motivates them and how they like to do things.
- If you want to speak to staff, it is a good idea to make an appointment. This usually works better than trying to catch them on the ward when they may be busy.
-  Bring someone with you to take notes and for support if you need it.
- Before a meeting, write down any questions you have. Don't be afraid of asking 'stupid' questions. For ideas of what to ask, see the HSE's **Patient Information Brochure (Code of Practice for Integrated Discharge Planning)** on [w: hse.ie](http://w:hse.ie) or from the hospital.
- Take your time. If you don't fully understand what the staff member is saying, ask them to explain it again.
- Staff should give you all the information and contact details you need for going home – see checklist on p 7.

Some options for care and living after hospital






In-patient rehabilitation - The National Rehabilitation Hospital (NRH) in Dun Laoghaire is the main in-patient rehabilitation centre in Ireland. Some other hospitals and stroke units in major hospitals also offer in-patient rehabilitation. Discuss with the hospital team if your family member can be assessed for the NRH (w: nrh.ie) or other in-patient rehabilitation centres. There is often a high demand for places and waiting times for those accepted.

Nursing homes or care facilities - if the plan is for your family member to go to one of these - ask the Hospital Social Worker, HSE Public Health Nurse or GP Practice Nurse for a list of facilities that cater for people with your family member's condition. There are a limited number of care facilities that have brain injury beds.

Selecting a nursing home or care facility - **Nursing Homes Ireland** has details of nursing homes that are registered members t: 01 429 2570 w: nhi.ie. You can also see useful state inspection reports on w: hiqa.ie.

Paying for a nursing home or care facility - the HSE usually pays some of the cost of long-term nursing home care. Ask the Hospital Social Worker for details, contact the **HSE** on **t: 1850 24 1850** or **Citizens Information** on **t: 0761 074 000** or **w: citizensinformation.ie**.

Going home - if the plan is for your family member to go home, these points may be useful:

1. **In most cases, it is the family who have the greatest responsibility for someone once they get home.** However, bear in mind that you are not obliged to become a carer. If you do decide to care for your family member, you may be entitled to some Social Welfare benefits. **A lot of people don't think of themselves as being 'carers'.** However, this is the term used for Social Welfare entitlements such as getting paid leave from work to be at home. Ask the Social Worker for details of what is available or see **w: citizensinformation.ie** or **t: 0761 074 000**.
 -  **A lot of people don't think of themselves as being 'carers'.**
 -  Ask the Social Worker for details of what is available or see **w: citizensinformation.ie** or **t: 0761 074 000**.
2. If you, or your family member, need services (Home help, for example) hospital staff should ensure these are in place before discharge. If your home needs to be adapted, the hospital OT will help you apply for any relevant grants or a loan. There may be a delay in getting these. You may wait until you are satisfied with the level of support at home before you agree to your relative's discharge. However, if enough supports are not in place, the hospital may recommend your family member go to a nursing care facility, even for a while.
-  Get further advice from the Hospital Social Worker or a **Brain Injury Information and Support Worker** in **Headway** on **t: 1890 200 278** or **01 6040 800**.

Leaving hospital checklist

| Check the hospital team have: | ✓ |
|---|---|
| 1. Answered any questions you have before you go home . Write down the answers (see p 4 and 6 for ideas). | |
| 2. Helped you, or your family member, to complete any forms you need. | |
| 3. Given you prescriptions for your family member's medications and a full list of their medications. | |
| 4. Given you phone numbers for hospital staff you, or your family member, can contact with any questions once you get home. | |
| 5. Given your family member a follow up appointment with their consultant (usually in 6 weeks' time). | |
| 6. Sent a discharge letter to your GP . This has a summary of your hospital treatment and any follow up services the hospital has referred to you. | |
| 7. Contacted the Public Health Nurse if needed. | |
| 8. Referred your family member to any HSE Primary Care Services they need (such as Home Help, Speech and Language, Physiotherapy, Occupational Therapy, Counselling, Psychology, Personal Assistance, The Disability Services Manager or Older Person's Services Manager). | |
| 9. Referred you and/or your family member to any Brain injury or other relevant not-for-profit services (see p 16, 18 and 38). | |

To Do's for you:



1. Get a copy of **Getting what you need after a brain injury** from the hospital or Headway. This free pocket leaflet tells you who to contact for the services and supports your family member, or you, may need. This includes legal and financial issues, Social Welfare payments, grants, returning to work & driving. **t:** 01 6040 800 **w:** headway.ie
2. Put the **Citizens Information** number into your phone. They give free and independent advice on all **public services and entitlements** and help with application forms.
Lo-call t: 076 107 4000.
3. **Make a list of things you need to be done.** Then when friends or family offer to help, ask them to do something on the list.
4. Note down **important phone numbers** or save them in your phone.
5. Use a **folder** to keep all your family member's information and medical documents in one place.
6. Get a **large wall calendar** and/or a **whiteboard** so everyone at home can see what appointments and other things are planned.
7. Use a **diary** to note upcoming appointments or put reminders into your phone.
8. If your family member has **a lot of medications**, ask your pharmacy to put them into **daily dose packs**. This service is often offered free of charge.



It can be hard to judge now what you might need at home. So, it's a good idea to accept referrals to any services offered. Waiting times can be long. You can always turn a service down later if you find you, or your family member, do not need it.

The professionals – who is who?

- ① For a referral to professionals working in the HSE, or in not-for-profit services, ask hospital staff or your GP. HSE t: 1850 24 1850 and opposite for more details.
Private consultants – ask your GP or see hospital websites.
Private therapists – see this page and page 10.
Note: This is not an exhaustive list. Ask your GP who can give support for any other issues not covered here.
For details of professionals working in the area of intimacy and sexual function, see page 32.

A **Neurologist** is a consultant doctor specialising in brain disorders.

A **Rehabilitation Medicine Consultant** is a public doctor who leads a team working on a patient's rehabilitation.

The **HSE Primary Care Team** provides care at home and includes the GP, Public Health Nurse, Occupational Therapist, Physiotherapist and Speech and Language Therapist.

The **Public Health Nurse** provides care and is the main point of contact for the Primary Care Team and Home Help and Respite care. The hospital or your GP can refer your relative.

Occupational Therapists (OTs) work with people to develop the skills they need to live as independently as possible. For private OTs, call **t:** 01 874 8136 or see **w:** www.aoti.ie

Physiotherapists work to improve movement, mobility and coordination. For private physiotherapists, phone **t:** 01 402 2574 or see **w:** cphp.ie.

Speech and Language Therapists assist people with their swallowing, speech and communication. For private Speech and Language Therapists, see **w:** www.isti.ie.



Not-for-profit services (such as Headway) have a range of staff who offer support, rehabilitation and training in the community. Staff may include Counsellors, Rehabilitation Officers, Social Care Staff, Case Managers, Psychologists and Neuropsychologists, Rehabilitation Assistants, Community Re-integration Officers and Vocational Rehabilitation Specialists (re work). See pages 16, 18 & 38.

A **Psychiatrist** is a doctor specialised in mental health.

A **Neuropsychiatrist** has further training in how brain disorders affect behaviour and mental health. A brain injury sometimes affects an existing mental illness or causes one to develop. If this happens, treatment by a Psychiatrist (or Neuropsychiatrist where available) may be recommended.

Clinical Psychologists are trained in a range of mental health issues. They provide rehabilitation, talk therapy and assessments to help a person to better understand what their cognitive strengths and weakness are. See **w:** psihq.ie or phone **t:** 01 472 0105.

A **Neuropsychologist** is a Clinical Psychologist with further training in how brain disorders affect thinking and behaviour.

Counsellors and **Psychotherapists** work with people to explore their needs and emotions during difficult times. They also help them to develop ways of coping with challenging situations, emotions or thoughts. See p 32 for contact details.

Social Workers give practical and emotional support to patients and their families. In hospital, they assist with entitlements and referrals to other services. At home, Social Workers support some families facing challenging situations.

The **HSE Disability Manager or Older Persons' Services Manager** (for over 65's) oversee health care services after someone leaves hospital. They are particularly important when someone has many needs (**HSE t:** 1850 24 1850).

Notes

[illegible]

Back at home

Getting back home can be a relief. This is likely to be a demanding time for you and your family member – many people say they wish they had realised when they got home that this was not the end of the recovery but the beginning of a new phase. Try to remember your own needs and to look after yourself as well as other people.

Use the letters H-O-P-E to remind you what can help

1. Accept **Help** – it may be easier to accept help if you tell yourself that even if someone else can't look after your family member or do something as well as you, the important thing is it gets done.
2. Be **Organised** – for example, prioritise (only do the most important things), use lists, a note book, a folder for documents, freeze extra portions of meals and give jobs to willing friends, family or neighbours. See the printable sheets at [w: headway.ie/information](http://w:headway.ie/information) - **Day Planner, Task Planner and Appointment Planner**.
3. Have **Patience** with yourself and your family member.
4. Use your **Energy** wisely. Don't argue over small things or constantly correct your family member if their memory has been affected. Try to resist the urge to do too much for them. The more they can re-learn to do themselves, the more independent they can become.

The key things your family member needs now are:

Rest - see page 19 for tips.

Routine – see pages 17, 26, and 33 for tips.

Reduced stress – try the tips on page 28 and 29.

Common things your family member may experience now

- Worry about symptoms and their health (see p 15).
- Having headaches, pain, being sensitive to light, noise or changes in temperature (see p 16, 18 & 21).
- Feeling very tired and sleeping a lot (see p 19).
- Getting frustrated, irritable or angry with themselves, things or other people (see p 20, 21 and 22).
- Forgetting things, losing things and having difficulty concentrating and being organised (see p 16 and 17).
- Feeling overwhelmed by visitors, busy places, too much information or making decisions (p 19 and 21).
- Needing things to be done in exact ways (see p 26).
- Having mood swings and crying easily. Some people may become unemotional, while others may have difficulty expressing feelings (see p 20-22).
- Feeling that no-one understands what they are going through (see p 10, 21 and 38).



Some of these changes may improve over time. On p 15-34, we give you lots of suggestions for coping and ways to take care of yourself.



Try not to take it personally if your family member is nice to visitors and then irritable with you. Like you, they are probably tired and stressed but may not be able to deal with those feelings as well as before. It is not their fault and it's not yours either.

Getting services and support

It may be a few weeks or months after your family member gets home before it really becomes clear what support or services you, and they, need. Check back to see what HSE or not-for-profit services you were referred to. The Hospital Social Worker, your GP or your Public Health Nurse should know if you can't remember. See p 38 for what **Headway** offers and p 15, 16, and 18 for other organisations. **Getting what you need after a brain injury** shows lots of services at a glance (see p 8).



HSE community services vary from area to area and there are often waiting lists. People with Medical cards may be prioritised. However, all Irish residents are entitled to apply for HSE services such as the Public Health Nurse, OT, Physiotherapy and Speech and language (**HSE t: 1850 24 1850**). If **paying privately** is an option, see page 9 and 10 for contact details for private practitioners. Some offer home visits.



If you need a break from caring, ask the GP, Public Health Nurse or HSE Disability Manager. They may be able to help you access **respite care** for your relative. Waiting times may apply (p 9 & 10 for contact details).



If you, or your family member have difficulty getting a service you believe you are entitled to, you can:

- **Appeal** if you've been refused a public service, grant or Social Welfare Payment.
- Ask for the **Access Officer** in any government department or public service (including the Council).
- Contact the **National Advocacy Service for People with Disabilities**. **t: 076 107 3000**
w: citizensinformationboard.ie

Coping with changes

A brain injury may bring a lot of difficult changes. Remember that not all of the changes covered in this section will affect your family member. Focus on what they can still do and still enjoy. Try to help them to use these strengths to develop new ways of managing.

Bear in mind that there is no one solution or 'right' way that suits everyone. Try to figure out what works well for you and your family member. Encourage them to be as independent as they can.

“Life is not what it's supposed to be. It's what it is. The way you cope with it is what makes the difference.”

Virginia Satir, Family Therapist and author

Things you can do about common issues

- **Symptoms** - if you are worried about any symptoms, note them down. If they do not ease, contact your GP or hospital team. If your family member develops any sudden symptoms such as difficulty speaking, a severe headache or weakness on one side, phone 999.
- **Medication** - it is important your family member takes these in the way their doctor prescribed. If they have a lot of tablets, ask your pharmacy to put them in to daily dose packs. Alcohol can interfere with prescription medication. Check the pack or talk to your GP (see page 36 for more on alcohol).

- **Seizures** – if your family member has had a seizure or has epilepsy, phone their Epilepsy Nurse Specialist or your GP with any questions. **Epilepsy Ireland** also have a Helpline t: 01 455 7500. If your family member has their first seizure at home, try to stay calm, **don't put anything in their mouth** (they won't swallow their tongue) and call an ambulance.
- **Headaches** – are common after a brain injury. In most cases, they are treated with pain relievers the same as other headaches. Ask your GP for advice. Gentle exercise and managing stress may help. **The Migraine Association of Ireland** provides information and support to headache sufferers - t: 01 894 1280.

Changes in cognitive skills - thinking, organising, communicating and memory



After a brain injury, difficulties in this area can cause challenges in living everyday life. You, and your family member, can get lots of useful tips and advice in these Headway booklets online or in print: (1) **Attention and concentration** (2) **Planning and organising** (3) **Memory** and (4) **Communicating after a brain injury**.



A Psychologist or Occupational Therapist can assess your family member's skills such as memory, attention and reasoning and suggest approaches for any areas needing support (see p 9 & 10).

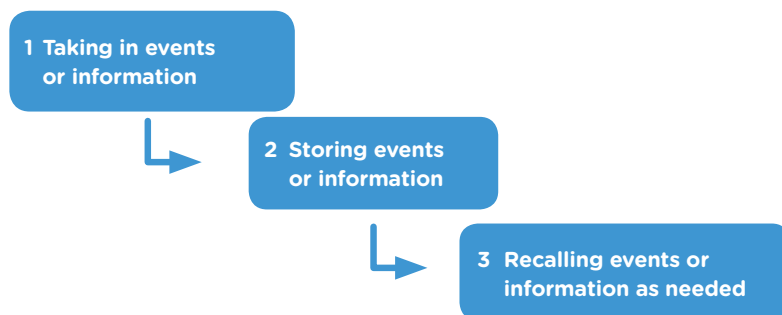
“Remember to ask questions and to enquire about what services are available.”

Aisling, Co Cork

Communicating - if your family member's communication has been affected by their brain injury, follow their Speech and Language Therapist's advice. These tips may help:

- Choose somewhere quiet and face your family member. If you keep up comfortable eye contact, this can help you both to see if you understand each other.
- Ask one question at a time. Wait for them to answer before asking another question.

Memory problems are one of the most common difficulties that people experience. This diagram shows simply how memory works. A brain injury can affect one or more of these steps:



There are no quick fixes for memory difficulties but these things may help: (1) Get into a routine. (2) Keep things in the house in agreed places as much as possible. (3) Reduce clutter. (4) Use things to aid memory such as to-do lists, a diary or phone, a wall-calendar and notebook and (5) Encourage your family member to eat healthily, exercise, get enough sleep and learn ways to cope with stress or changes in mood – see p 19, 28 and 29.



Headway's booklets **Communicating after a brain injury and Living with changes in your memory** have further tips and advice (available online and in print).

Physical and sensory changes

It can take you and your family member time and effort to adjust to mobility difficulties or changes in things such as sight, hearing, touch, temperature regulation (becoming hot or cold easily), appetite and sense of taste or smell.



Try to think of adjusting to these changes as part of a learning process rather than seeing any set-backs or difficulties as 'failures'.



If you and/or your family member, need more support, write down what the issues are and ask the Public Health Nurse or GP for further assistance.



Not-for-profit organisations that offer relevant services, information and support:

- **Mobility - Irish Wheelchair Association**
t: 01 01 818 6400 w: iwa.ie
- **Seizures - Epilepsy Ireland** t: 01 455 7500. Epilepsy Nurse
Infoline - Monday mornings t: 01 455 4311.
- **Sight changes - NCBI** t: 01 830 7011 w: ncbi.ie
- **Headaches - The Migraine Association of Ireland**
t: 01 894 1280 w: migraine.ie
- **Hearing changes - Deaf Hear** t: 01 817 5700
- **Pain - Chronic Pain Ireland** t: 01 804 7567
- **Stroke nurses - Irish Heart** t: 1800 25 25 50 w: irishheart.ie
- **Brain tumour support** (including benign tumours)
Irish Cancer Society t: 1800 200 700 w: cancer.ie



Bear in mind that any medical or therapy appointments are likely to tire out your family member. Plan time for them to rest afterwards.

Tiredness (fatigue)

For the first few weeks your family member is likely to feel very tired. This is to be expected as their brain is still recovering and they are adjusting to being home. Fatigue also affects many people long-term. We don't understand all the reasons for this but one is that the brain now has to work harder to do everyday things.

Fatigue can affect thoughts, feelings and what we do
These tips may help:

Think

- I cannot take in information.
- I get overwhelmed in busy situations.
- My brain feels like it is 'in a fog'.

Feel

- Guilty — 'I shouldn't be like this.'
- Judged by others — 'They think I'm lazy.'
- Fearful that my fatigue will not improve.

Do

- I am not able to return to work right now.
- I slur my words when I am over-tired.
- I do not have enough energy to go out.

- Expect that your family member may become tired very quickly and need to rest.
- Do important things when they are at their freshest.
- Try to have 'quiet' times. Switch off the radio and TV.
- Remind visitors that even if your family member looks well, they need to pace themselves and get lots of rest.



To get more information and advice, see Headway's booklet **Living with changes in fatigue and sleep.**

Personality, behaviour and mood changes

Changes can happen to your family member's personality because the 'brakes' or 'filters' which control their behaviour or emotions have been damaged. Difficult behaviour can also be a way that they express the upset or frustration they feel from living with their brain injury. Another reason may be that your relative has found out that, if they behave in a certain way, they will get what they want or need. They may not even be consciously aware that they are doing this.

Common changes are:

- Angry outbursts or using bad language.
- Doing inappropriate and/or hurtful things.
- Becoming withdrawn.
- Refusing to wash or change clothes.
- Disinterest in family events or activities.

Most family members find changes in personality or behaviour much more challenging than other difficulties. If you find you are having mixed feelings about the injured person, this is very understandable. It is normal to be upset by your family member's behaviour and to feel a sense of loss for the parts of their personality that have changed. See p 35 for more on this and p 10 and 38 for sources of support.

“Try not to argue – let things go over your head (even though this can be hard at times). Take it one day at a time – even one hour at a time. My other piece of advice is not to hide things from your family or other people.”

Mary, Co Cork

Anger, irritation and mood swings

Frustration, irritability and anger outbursts may be due to damage to the parts of the brain that control emotional behaviour. Your family member may also feel under pressure, tired or irritable due to the extra effort needed to do everyday things.

Other things that may trigger anger include:

- Pain, headaches, hunger.
- Noise & busy places.
- Changed self-image.
- Feeling angry about the accident or injury.
- Worries about the future.
- Changes in relationships and social activities.
- Frustration (personal and /or sexual).
- Information 'overload'.
- Lack of understanding from friends, family, and/or professionals.
- Feeling stressed due to many medical or legal appointments.



Things to try

Ways that may help to manage anger

- Learn to spot the early signs of your family member becoming angry - for example, fast breaths or clenching their jaw. Practice trying to distract them before the anger develops into a full outburst.
- Check if you are contributing to the anger - for example, by criticising or pushing them to do things they are not capable of or don't feel confident about. Try to focus on what they are doing well, rather than on any mistakes.
- Try to notice what triggers the anger. Change as many triggers as you can - for example, take over dealing with household bills or switch off the TV when you are trying to talk to your family member.

When someone is angry

- Avoid trying to reason with your family member when they are at their angriest. Give them space.
- Go into another room if you need to. If you feel in any danger, remove yourself immediately.
- If they are too upset to sort out what is making them angry, distracting them may work - for example, suggesting doing something else.



Headway's booklet **Anger, irritability and mood swings** has more detailed tips, information and advice for your family member and you. It is available in print or online from headway.ie.



Mood swings are where a person's emotions change quickly and noticeably. This is known as Emotional lability. The person may be crying one minute, laughing the next, sometimes without actually feeling happy or sad. It may help to get advice from your GP or a psychologist and to read the Headway booklet above.



Taking care of yourself

- Try not to take it personally when anger is directed at you. Remind yourself that this behaviour is part of your family member's brain injury.
- If you find yourself getting angry, breathe slowly, count down from 10 and try to direct your feelings at the injury, instead of at your family member.
- See the stress-relieving tips on p 29 for other ideas.
- Try positive ways to deal with your feelings - for example, taking exercise, talking to a friend or doing something else you enjoy.



Most people's instinct is to try to stop their family member from acting in a certain way. Bear in mind that often only some change in behaviour will be possible. It may help you to cope if you also look at **changing how you feel about what they do and how you react to it**. See p 24 for a **Key point** on this.

Inappropriate social behaviour

This is where a person cannot control, or can only partially control, what they say or do. The reason may be an injury to the Frontal lobes of the brain. They may act without thinking or say the first thing that comes to mind. The person may also no longer realise that what they do affects other people. If your family member behaves like this, it can be frustrating and embarrassing.



Things to try

- First, try ignoring inappropriate comments or behaviour. The lack of feedback from you may be enough to prompt your family member to stop the inappropriate behaviour or to do it less often.
- If ignoring the behaviour does not work, tell them that they are behaving inappropriately – either at the time or immediately afterwards.
- Bear in mind that your family member may not understand why their behaviour is unacceptable. Also, they may find it difficult to change their behaviour.



It may be useful to get input from a psychologist for your family member or yourself (see page 10 for contact details).



Try not to take the behaviour personally or feel it reflects on you. Remind yourself that it is the brain injury that is to blame - not your family member.



You are not responsible for what your family member says or does. If they are not able to change their behaviour and it is affecting your everyday life, doing a type of talk therapy called **Cognitive Behavioural Therapy** may help you cope by changing how you **feel** about what they do. Contact details for counsellors and psychologist are on p 10.

Lack of insight

- This is where a person's ability to understand and judge their strengths and weaknesses is impaired.
- Lack of insight may be due to how recently they were injured. Their insight may increase over time.
- It can also happen due to damage to the Frontal lobes of the brain. In this case, the person's insight may not increase over time or only improve a bit.



Things to try

If your family member wants to do something that you know they are not able to, allow them (where safe) to try. If they fail, it may help them understand their limitations. Seeking input from a psychologist may be beneficial. **If they want to drive**, they may accept the results of a Driving assessment done by an OT better than being told by you or their GP. See page 36 and Headway's



booklet **Returning to driving** for more.

Rigid thinking and inflexible behaviour

This is where a person has difficulty in being flexible in what they think or do – for example, having fixed routines or being unable to change their mind even when circumstances change. This behaviour is often due to an injury to the Frontal lobes of the brain.



Things to try

- Avoid any sudden changes in routine if you can.
- It may be possible for your family member to make changes they feel in control of. Try talking it through with them. Seeking a psychologist's input may help.
- If they get 'stuck' repeating themselves, asking them a question or to do something, may help them stop.



'Choose your battles' – in other words, tackle only the behaviours you find most difficult. Let other things go. Try to stay calm and remind yourself it's not deliberate.

Depression and anxiety

Many people experience depression or anxiety after a brain injury. Reasons include damage to a specific area of the brain or the person coming to realise the full impact of their injury. Feeling unmotivated or having difficulty getting started on things (known as **initiation**), may be directly due to the brain injury and/or to depression.

Try asking your family member how they feel and get advice from your GP or a psychologist. Talk therapy (psychotherapy), self-help and/or medication may help.



Headway's **Feeling low or anxious booklet** has useful advice and information (available in print or online).



Understand that anxiety and depression are common effects of a brain injury. Seek support and try ways to mind your own mental health, keep in touch with friends and manage stress (see p 28 & 29).

Being self-centered and lacking empathy

A brain injury can affect a person's communication, memory, attention and social skills. This may make them less aware of other people's feelings and needs. They may also lose the ability to empathise - to identify with other people's emotions. These difficulties can make them seem insensitive and self-centered. It is important to understand that they are not being intentionally selfish. This behaviour is often a direct result of an injury to the brain's Frontal lobes or linked structures.



Things to try

- Encourage your family member to understand what they need to do and say to keep up relationships. This may not be obvious to them.
- They may need to re-learn their social skills and practice communicating. Doing group activities or joining a Brain Injury Group may help improve these skills. Headway can direct you to any local groups.
- Try to bring your family member's attention to how you or other people feel - for example by asking: 'John seems in bad form today. What do you think?'.
- If they are being too demanding, set limits and explain why - for example, 'I can't give you a lift now because I am working. I can bring you in an hour.'



Taking care of yourself

- Tell people you trust how this issue is affecting you - they may not realise what you are going through.
- Consider seeking counselling with someone experienced in brain injury (see pages 10, 32 and 38).
- If you want to talk to someone in confidence, you can also phone Headway's Helpline on **t: 1890 200 278**.

Notes

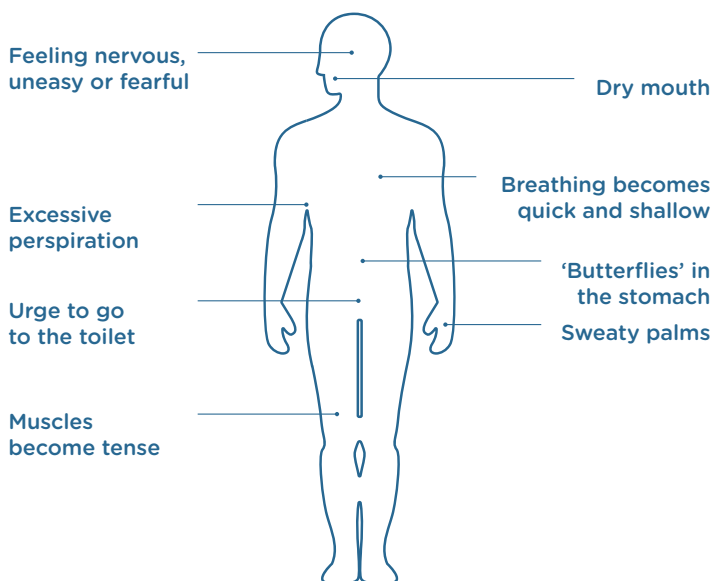
[illegible]



Looking after your own well-being

When a family member has a brain injury a lot of extra responsibility can fall on your shoulders. It is possible to become stressed, or even unwell, from the demands on your time, energy and emotions. However, if you find ways to manage stress, your thinking, mood and emotions, it may help you to feel better and to cope better.

Some signs of being over-stressed are:



Keeping up with your own interests and friends can help you look after your own well-being, as can learning relaxation techniques like meditation or breathing. See the next page for suggestions of ways to fit stress-reduction into your daily routine. If you need professional help, such as talk therapy (counselling) to manage stress or feeling low, it is not a sign of weakness (see p 29).

Tips for staying calm and managing stress

1. **Setting up a routine** can be reassuring and help you and your family member to cope with changes from the brain injury. Include enjoyable things if you can.
2. Learn to **recognise the signs of stress** (see page 28) and do something to relax, even for **five minutes**.
3. **Breathing** exercise and meditation may make you feel calmer. There are many tips and tools online and classes available in most communities.
4. Take **exercise** when you can. Things you can try at home are skipping, stretches, jogging on the spot, yoga or even energetic housework. Also, try to **eat as regularly and healthily** as possible.
5. **Talk** to someone you trust about how you are **really feeling**. If you want to **talk to someone else**, contact a Family members support group, Headway, your GP or a counsellor (see pages 10, 32 and 38). Some people find it also helps to **write down** what they are feeling in a **diary** or a **notebook**.
6. **Try to be realistic** about what you expect from your family member and how much they will progress.
7. **Remind yourself that you are human** and we all have our limitations. Don't compare yourself to others - you are doing your best. If you need more support, see pages 9, 10, 14, 16, 18, 32 and 38 for who to contact.

“Remember to ask yourself: ‘What about me?’ It’s ok to think about yourself and what you need too.”

Ruth, Dublin

[illegible]

Relationships and intimacy

If you are in a relationship with a spouse, partner, boyfriend or girlfriend who suffers a brain injury, it can bring strain into your lives that neither of you expected. Many relationships come under pressure after a brain injury because of this. If you or your partner are finding things difficult, or if any previous problems you had are now worse, consider seeking professional support. See the next page for contact details.



Headway's booklet **Relationships and intimacy** is designed for people who have had a brain injury to read and use with their partners. Get it online or in print from headway.ie/information.


Some advice that may also help is:

- Bear in mind that it takes time to accept new life situations. **Try to be patient** with yourself and your partner. Give each other time to adjust.
- **Focus on the things and people that help you to stay strong as a couple.** This might be keeping in touch with supportive family members, meeting up with friends or doing activities you enjoy together.
- **Try to let unimportant things go.** Arguments often happen because your partner frequently feels frustrated, tired or irritable because of their brain injury and you are tired and stressed as well.
- **Try to talk** any difficulties through together. If you find it too hard to talk, seeing a counsellor as a couple or on your own, may be helpful. See the next page for contact details.

Intimacy and sex

Many couples find being intimate and having sex after a brain injury difficult. It is quite common for people with a brain injury to have less interest in sex, difficulties with sexual arousal, intercourse or orgasm. The reasons may be physical, hormonal, emotional, psychological, related to medications, or a combination of these.

Some people may be sexually disinhibited – eg, making comments in public or touching inappropriately. This is more common early in recovery and usually resolves.

 If any issues are bothering you and do not resolve, seek advice from your GP or nurse, a Psychologist, a Counsellor or a Sex Therapist.

- The **Sexual Wellbeing Service** in the **National Rehabilitation Hospital**, Dun Laoghaire, offers specialist sex therapy, counselling and advice to people affected by a brain injury
t: 01 2355 288 **w:** nrh.ie.
- To find a **registered Sex Therapist in Ireland** contact the **College of Relationship and Sexual Therapists UK**
t: 0044 208 543 2707 **e:** info@cosrt.org.uk.
- **Public Psychologists or Counsellors** – ask your GP or Public Health Nurse or phone **HSE t:** 1850 24 1850.
- **Family Resource Centres** provide low-cost or free counselling.
t: 01 4200 580 **w:** familyresource.ie.
- **Accredited Private Counsellors**
t: 01 230 3536 **w:** irish-counselling.ie.
- **Registered Private Psychologists: Psychological Society of Ireland t:** 01 472 0105 **w:** psihq.ie.
- **Headway** offers brain injury and family services.



Helping children and teenagers to adjust

When a close family member has a brain injury, like the adults, children and teenagers can be affected. They may be going through strong emotions such as initial shock and fear, and then possibly guilt, anger or even resentment. It is important to reassure your child or teenager that that you, and the injured person, love them even if things are difficult.



Tips for helping children to adjust

- **Explain what is happening.** Children (even very young ones) can sense when something is wrong. You can tell them about the brain injury and how it is affecting your family member in ways they understand.
- **Be prepared** that your child may start acting as if they are younger than they are, begin behaving badly or start attention-seeking. This can be their way of saying 'I'm upset', 'I don't understand' or 'I need looking after too'. Try to be patient with them.
- **An activity** like making a book about their family, drawing or playing **may help your child to express their feelings about what is happening.**
- **Tell your child the brain injury is not their fault**, even if they don't bring it up. Many children worry the injury happened because of something they did.
- **Try to keep up routines, discipline, activities and time with friends** and as much as possible. Routines and boundaries are reassuring during times of stress.



Children aged 7 to 12, you might like to read Headway's **Kid's Guide to Brain Injury** with you or on their own. Designed with illustrations and easy-to-follow text, it aims to answer the questions that children often have when a parent or other adult has a brain injury (available online or in print).



Tips for helping teenagers to adjust

- **Ask your teenager what they want to know.** Encourage them to read Headway's graphic novel-style **Teen's Guide to Brain Injury**. It covers the common concerns that teenagers have and talks about ways they can deal with their feelings. Headway's booklet, **The brain and brain injury** has clear information and diagrams.
- Be prepared – they may say **they don't want to know anything about brain injury**. Don't force them. Read our **Teen's Guide** yourself anyway.
- Tell your teenager that **they are not responsible** if your family member's behaviour is difficult (arguing, shouting, or being angry or inappropriate).



Tell the school how the brain injury is affecting your family. Teachers can be a support if your child or teenager gets teased or if their work or behaviour changes. These issues are likely to improve over time as they adjust.



If you feel you, your child or your teenager need further support, see pages 10 and 38 for who to contact.

Moving forward – you

It may be many months after your family members' brain injury before you get a chance to 'take stock' and to think about how life is. It can take time to realise the full impact of what has happened and to find ways of accepting it.

Each family copes in its own way. Some people say the months after a brain injury feel like being on an 'emotional roller-coaster'. One day they are feeling sad thinking 'if only...' and the next day, feeling elated because their family member has made some progress.

Many people go through a kind of grief for the loss of the person as they were before their injury. This can feel like a form of bereavement. So much is uncertain during recovery, and progress can stop and start, so these emotions can come and go in waves.



Talking about your feelings with family, friends, other people affected by a brain injury, a counsellor, your GP or a psychologist may help (see p 10 and 38).



Free time is important for your own well-being. If you are not getting enough time to yourself (or any), set yourself a goal of getting some. This may take a bit of effort. To help motivate yourself, make a list of things you want to do in 'your' time. Then make a plan of how you and/or other people can help free up some of your day or week. Put your plan in to action. Enjoy your free time. You deserve it.

“As a carer, you need to take time out for yourself. Accept any help that is offered.”

Olive, Dublin

Moving forward – your family member

Issues that may be relevant to your family member:

Alcohol – drinking is not generally recommended because an injured brain is much more sensitive to the effects of alcohol. Your GP can give advice on this.



You and your family member can also get the facts from Headway's **Alcohol after a brain injury booklet**.

Driving - Your relative must get their doctor's approval and inform their insurer before returning to driving. Their insurance premium should not increase in most cases. Getting a Driving Assessment done by an Occupational Therapist can show your family member if they are safe to drive.



For further information, see Headway's **Returning to driving** booklet online or in print. It also deals with the issue of people who cannot go back to driving.

Work - Wanting to get back to work can be a big motivation for many people as they recover. One frequent mistake is going back to work before they are ready. In reality, many people face having to change their job or consider other options such as re-training or volunteering.



For lots of useful information and advice, see Headway's **Returning to work and other activities** booklet or phone us on 01 6040 800.

Some final thoughts from Headway families and staff

- Take things one step at a time.
- Each member of your family has their own way of reacting to the stress of a loved one being ill. There is no right or wrong way to react. Try to accept that everyone is different and to be as patient as you can.
- Be realistic that a full recovery may not be possible but a meaningful and satisfying life can be.
- Give yourselves time. A brain injury happens quickly but it can take months or even years to adjust to it.
- Avoid thinking of things you get wrong in trying to support your family member as 'failures'. Learning from trial and error is how we figure out what works.
- Don't be embarrassed to ask for services or think that your family member's injury is not 'serious' enough. If you are coping with difficulties that are not obvious to other people, you may need just as much support as other families.
- Seeking help and information when you need it can save you a lot of unnecessary stress and worry.
- Finally, it is not all about the person with the injury. You, your life and your wellbeing matter too.

“In the beginning, I would have said so often: ‘Why me? Why our family?’ I felt as if our life was over. But as time has passed, I can see that life is not over – it has just changed. We have all gradually managed to adjust. The most important message I have for other carers starting out is that there is life after a brain injury - a different life but one worth living.”

Anne, Co Carlow

Help and information

Information and brain injury services

Headway is a not-for-profit organisation that offers:

- Free community-based brain injury rehabilitation and family member support in Cork, Dublin, Kerry, the South East and Limerick to people aged 18 and over.
- Further information on brain injury and how to get support where you live.
- Ways to connect with other people affected by a brain injury.
- **Headway National Helpline t:** 1890 200 278 or 01 6040 800
w: headway.ie

Acquired Brain Injury Ireland

Acquired Brain Injury Ireland offer assisted-living, case-management and community rehabilitation services to people with brain injuries, aged 18-65. **t:** 01 280 4164 **w:** abiireland.ie

Irish Heart

Irish Heart run a Heart and Stroke Nurse Helpline. They also run stroke clubs and support groups for people with strokes and their family members. Helpline **t:** 1800 25 25 50 **w:** irishheart.ie

Family Carers Ireland

Family Carers Ireland provides services and supports to family members, including young people under 18. **w:** familycarers.ie
t: 1800 240 724

BRI

BRI is an organisation run by people affected by a brain injury. They offer support and hold groups in some counties in Ireland. **t:** 01 482 4802 **w:** briireland.ie

HSE information line t: 1850 24 1850 **w:** hse.ie

Citizens Information t: 076 107 4000 **w:** citizensinformation.ie

[illegible]

“Believe that things will get better for you and your family member. What I learned is that if you change and adapt to your circumstances, you can surprise yourself with what you achieve.”

Frances, Co Dublin

“Believe that things will get better for you and your family member. What I learned is that if you change and adapt to your circumstances, you can surprise yourself with what you achieve.”

Frances, Co Dublin

Index

| | | | |
|--|---------------|---------------------------|---------------------------|
| Alcohol | 15, 36 | Home, assistance at | 7, 8, 14, 18 |
| Anger & irritability | 20-22 | Hospital, stage | 2-8 |
| Appetite | 9, 17, 18, 29 | Inappropriate behaviour | 20, 23-26 |
| Attention & concentration | 3, 16 | Information 'overload' | 4, 13, 19, 21 |
| Anxiety | 26, 28, 29 | Insight, lack of | 24 |
| Behaviour, changes in | 20-26 | Intimacy & sex | 3, 10, 32 |
| Brain injury, effects of | 3 | Irritability | 20-22 |
| Care, paying for | 6, 8 | Legal issues | 8 |
| Carer, being a | 6 | Loss, feelings of | 20, 35 |
| benefits & support | 6, 8, 38 | Memory difficulties | 3, 16, 17 |
| Caring, getting a break | 9, 10 | Mental health, yours | 25, 26 |
| Children, coping | 33-34 | family member's | 3, 20, 26 |
| Cognitive changes | 3, 16, 17 | Mobility changes | 3, 18 |
| Communicating | 3, 16, 17 | Mood swings | 22 |
| with you partner | 17, 31 | Motivation, lack of | 26 |
| with professionals | 4, 6, 7 | Organising & planning | 12, 13, 16, 17 |
| Community services, HSE | 9 | Pain | 13, 18, 21, |
| Not-for-profits | 10, 18, 38 | Personality, change in | 3, 20 |
| Concentration | 3, 16 | Primary Care Team, HSE | 7, 9 |
| Counselling | 10, 29, 32 | Professionals, who is who | 9, 10, 14 |
| Depression & low mood | 26, 28 | Rehabilitation | 4-6 |
| Diary, family member | 17 | Respite care | 10, 14 |
| you | 29 | Services & support | 7, 8, 14-16, 18, 38 |
| Drinking - see Alcohol | | Sight | 3, 13, 18 |
| Driving | 24, 36 | Sleep & fatigue | 19 |
| Embarrassment, you | 23, 24 | Speech & language | 3, 9, 16, 17 |
| family member, lack of | 23 | Stress & relaxation | 21, 28, 29 |
| Entitlements & finances | 7, 8, 10, 14 | Thinking difficulties | 16 |
| Fatigue & sleep | 19 | Teenagers, coping | 33-34 |
| Further reading | 3 | Work, you | 6 |
| 'Getting what you need after a brain injury' | 8 | family member | 36 |
| Groups, support | 38 | You, getting support | 9, 10, 14, 16, 18, 32, 38 |
| Headaches | 13, 16, 21 | | |
| 'Hidden' difficulties | 1, 3, 15-26 | | |
| Hormones, changes in | 3, 32 | | |
| Home adaptations | 6 | | |

HEADWAY

Brain Injury Services & Support

Charity Number: CHY 7417

This project was approved by Government with support from the Dormant Account Funds.



web: www.headway.ie

email: info@headway.ie

tel: 1890 200 278 or 01 604 0800