



Brain injury rehabilitation in adults

A booklet for patients and carers

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Who is this booklet for and what is it about?

This booklet is for you if you have had a brain injury. Your family, friends and carers may also find it useful. This booklet is based on the recommendations from the SIGN national clinical guideline on brain injury rehabilitation in adults.

You can read more about SIGN on page 23 or by visiting our website at www.sign.ac.uk.

The information in this booklet adds to the information and advice the people involved in your care will give you.

This booklet explains:

- ★ what a brain injury is;
- ★ how you might be affected by a mild brain injury, and how it might be treated;
- ★ what treatments you might expect for a more serious brain injury;
- ★ where you might receive treatment;
- ★ what will happen when you leave hospital;
- ★ how you can get help when returning to work or study; and
- ★ what information carers might need.

It does not cover:

- ★ brain injuries in children; or
- ★ rehabilitation for people who have had a stroke.

What is a brain injury?

Brain injuries can be caused by a number of different things. A brain injury is a condition which is caused by 'non-progressive' damage to someone's brain which happens after birth and early childhood. Non-progressive means that the damage happens once and does not go on causing more damage.

A brain injury is sudden damage to the brain caused by things such as:

- ★ an infection, poisoning, or lack of oxygen (acquired brain injury); or
- ★ a blow to the head (traumatic brain injury), for example from:
 - ~ a road traffic accident;
 - ~ an assault;
 - ~ a fall; or
 - ~ a sports accident.

While a stroke is a kind of acquired brain injury and some of the information included in this booklet might be helpful for people who have had a stroke, this booklet focuses mainly on other types of brain injury. SIGN has published a separate guide for patients who have had a stroke and their carers, and you can read this on our website. www.sign.ac.uk/patients/publications/118/index.html

Most traumatic brain injuries are mild. For example, you might be unconscious for 30 minutes or less or have very brief memory problems which last less than a day. More severe injuries can cause longer spells of unconsciousness or memory loss which lasts longer than a day.

A severe brain injury can affect your:

- ★ physical ability - for example, you may have difficulty walking or speaking;
- ★ cognition (ability to think) - for example, you may find it hard to concentrate or remember things;
- ★ behaviour - for example, you may behave in a different way than before;

- ★ emotions - for example, you may find it hard to show affection or you may get angry much more easily; and
- ★ social ability - for example, you may find it hard to be with groups of people, or to make friends.

Sometimes people with severe brain injuries can have some of the same problems as people with milder injuries, although these might last longer or cause more difficulties with everyday activities. (Please see page 5 for a list of symptoms caused by mild brain injuries.)

After a brain injury, you will receive rehabilitation. This is the process of helping you to recover from the injury and getting you as close as possible to how you were before the injury.

The aim of rehabilitation is to help you overcome or cope with the problems caused by your brain injury.



If the injury is mild how might I be affected?

If you have had a mild traumatic brain injury (such as bumping your head on a low door or when getting into a car), you may have some of the following symptoms.

- ★ Headache
- ★ Feeling sick
- ★ Tiredness
- ★ Difficulty sleeping
- ★ Dizziness
- ★ Irritability
- ★ Difficulty concentrating, thinking clearly or remembering things
- ★ Sensitivity to light or noise (or both)

For most people these symptoms are normally not serious and will settle down quickly, usually getting better within three months. There is usually no need for any tests or treatment. As with any injury, it takes time for the brain to heal. You should be able to get back to your normal activities gradually.

Your general practitioner (GP) will need to know if you have had any other illnesses or injury before your mild traumatic brain injury, and if you drink alcohol or take illegal drugs. It is important that your GP knows about this to help them decide what to do next.

If you have symptoms which do not settle, your GP should check for any other causes which may need treatment, such as thyroid disease (a condition that affects the way the thyroid gland works).

If you experience anxiety, nightmares, flashbacks or low mood for more than three months after your brain injury, you should tell your GP about this. They may arrange for your symptoms to be assessed.

How will a mild brain injury be treated?

In most cases, your symptoms will get better without treatment, but your GP might offer you an antidepressant drug, which can help with headaches as well as low mood. If your symptoms have not improved without treatment, you may be offered a psychological therapy.

Psychological therapy is the name given to a range of treatments that usually involve talking one-to-one with a therapist. Cognitive behavioural therapy (CBT) is one type of therapy which may be helpful. It focuses on how your thoughts, feelings and behaviour influence your mood. It involves working with a therapist who will help you move away from thoughts and behaviours that cause your low mood.



If my brain injury is more severe who will be involved in my treatment?

If you were unconscious for more than 30 minutes after your head injury, or you had memory loss lasting a day or longer, your injury is classed as moderate or severe. You should be seen regularly by members of a health team specialising in brain injury, who will work together to arrange treatment and provide support for different parts of your recovery. This team is likely to include:

- ★ doctors;
- ★ nurses;
- ★ psychologists (professionals who specialise in the study of the human mind and behaviour);
- ★ physiotherapists (healthcare professionals who use physical methods such as massage and manipulation to promote health and well-being);
- ★ orthotists (healthcare professionals who use fitted devices to help with or restrict movement to correct the shape or function of the body);
- ★ dietitians;
- ★ occupational therapists (healthcare professionals who help people to get back into work and other activities); and
- ★ speech and language therapists.

Your team may also include other specialists.

Rehabilitation after brain injury works best if it is started soon after the injury. Rehabilitation may take a great deal of time and effort from you and the people supporting you.

How will movement problems be treated?

If you have had a moderate or severe brain injury this may affect your balance and movement, leading to problems with walking and other everyday activities.

Research has shown that practising everyday tasks over and over again is helpful. Your healthcare team may encourage you to practise walking, getting from sitting to standing or lifting or moving small objects with your hands and fingers. Practising everyday tasks is more helpful to your recovery than doing general exercises.

If your joints are not in the right position because of tightness in the muscles, it may help to wear a splint or a cast to prevent further tightening and improve the position of your limb. Splints are removable supports made of plastic or metal, while casts go around the whole limb and are normally made of plaster. You may also be given exercises to stretch your muscles.

You may be offered injections of Botulinum neurotoxin (sometimes called Botox, Dysport or Xeomin) to help with tight muscles. It is best for the doctor who is giving the injections to work with your physiotherapist or your occupational therapist (or both) so that together they get the best result from the effect of your injection.

Your doctor may also consider giving you the medicines baclofen and tizanadine to help ease tightness in the muscles following your brain injury.

What about bladder or bowel problems?

Some people have problems controlling their bladder or bowels after a brain injury. It is important that the hospital team assess your bladder and bowel control at the start of your rehabilitation.



How will problems with memory, attention and planning be treated?

A brain injury can lead to difficulties with memory, concentration and problem solving.

If you have memory problems after your brain injury, your healthcare team should train you to use some techniques to help with this. The techniques should focus on the things you need to remember each day rather than trying to improve your memory in general. If your memory problems are mild or moderate, your healthcare team may teach you to use memory aids, such as a diary, or ways of mentally organising items, for example using pictures to help you to remember things.

If your memory problems are severe, the treatment should focus on using memory aids to help you remember the things that are particularly important to you in your day-to-day activities.

If you have difficulty concentrating you should be taught ways of dealing with this using situations from your own day-to-day life.

You may have difficulty with planning, problem solving and setting and achieving goals. Your healthcare team should help you to set goals relating to the things you want and need to achieve in your day-to-day life. They will ask you to think about your own home situation and what things could help you there.

How will emotional and behavioural difficulties be treated?

A brain injury can cause behaviour problems such as feeling agitated or aggressive. Lots of other things can cause feelings of agitation after a brain injury, for example pain, constipation, tiredness and emotional problems. Your healthcare team should investigate and reduce these possible causes before considering other treatments for the agitation.

Propranolol is a medicine which is sometimes used for heart conditions and your doctor may consider using it to help treat moderate agitation or aggression. If so, they will recommend a low dose at first to see if it helps you.

A brain injury may lead to some people facing emotional problems, for example feelings of frustration, anxiety and depression. This can be quite difficult for the person and their families to recognise and understand, and to cope with, but often it is a normal reaction to a life-changing event.

Your healthcare team may offer you CBT to help with anxiety, fear and stress.



Who can help with communication problems?

A brain injury can affect communication in different ways, for example it may affect your ability to understand, speak, read and write. Some people can talk well but have difficulties taking part in conversations or being able to say the right thing at the right time.

If you have any of these problems, your healthcare team should refer you to a speech and language therapist who can assess and help manage these difficulties with you.



What if I have difficulty swallowing?

If you have problems swallowing after your brain injury, it is helpful to have an assessment to diagnose the problems and help plan your treatment. This is important because there may be a risk of you choking, or of food or drinks going down into your lungs instead of into your stomach. There are different kinds of assessment available and some involve X-rays or cameras.

Your speech and language therapist will decide if you need an assessment and, if so, which one would be most useful. Sometimes it is necessary to repeat assessments to check on your progress.



Where will I receive treatments?

Depending on the type of problems you have and how serious they are, you might be treated in any of the following places.

- ★ A hospital unit which specialises in rehabilitation only
- ★ A hospital which cares for people with a range of different health problems
- ★ In the community near to where you live

If you are treated in your local community, you should still have access to all the different types of medical and social services you need as part of your rehabilitation. You will have a named worker co-ordinating your care.

For some problems you can get help over the phone so you can stay at home. Your family and carers can also get support from healthcare professionals to help them to look after you and to stay positive themselves.



What happens when I am ready to leave hospital?

A well-planned return home from rehabilitation in hospital will help with your recovery, and planning your return home should be part of your treatment programme.

You and your carers should work with community staff and social services to plan your return home from hospital. The planning should take account of your particular home circumstances.

If necessary, you should have a home visit to check for problems that may affect your normal daily activities and to help plan your return from hospital.

If you need alterations to your home or aids (for example, handrails) fitted so you can live at home safely, the alterations should be carried out, and the aids fitted, before you leave hospital. Other, non-essential alterations may be carried out after you have gone home.

Hospital staff should give you a copy of the plan for your return home (known as a discharge plan), and should send a copy to all the staff who will be working with you after you leave hospital.

Once you leave hospital, you may be offered follow-up treatment, either in person or over the phone. This aims to help you to cope with any ongoing problems you may have with day-to-day activities or issues such as depression, agitation and aggression.

What about planning for return to work or study?

During your rehabilitation you should be thinking about the future, including work or study. Early in your rehabilitation you should have the opportunity to talk to someone about returning to work.

You can get support from healthcare professionals to contact your employer, and they can do this on your behalf if you feel this would be helpful.

With advice from your healthcare professionals you can decide what therapy and support you may need to return to work. It is a good idea to keep in touch with your employer during your rehabilitation.

There are organisations that can support you in your return to work or study and can give you information on employment rights and state benefits. These include your local Jobcentre Plus office and voluntary organisations which specialise in rehabilitation. Your healthcare professional can give you information on how to contact these organisations.

What about carers?

After your brain injury, family members may have difficulty understanding your problems and this can lead to stress or tension at home.

Young children can be confused and upset about your injury and may also need help and support. It is important that you and your family ask for help during your recovery.

Once you have left hospital, you may need a lot of support from a carer (partner, family member or friend) to allow you to live at home. They can get training and support to help them provide this.

The charity Headway has a range of fact sheets on their website for carers of people who have had a brain injury (www.headway.org.uk/caring.aspx).

Where can I find more information?

Scottish National Managed Clinical Network for Acquired Brain Injury

NMCN Team, 2nd Floor, Waverley Gate

2-4 Waterloo Place

Edinburgh EH1 3EG

Phone: 0131 465 5574

Website: www.sabin.scot.nhs.uk • Email: susan.whyte@nhslothian.scot.nhs.uk

The National Managed Clinical Network for Acquired Brain Injury is a Scottish national network that aims to improve the quality of services for children and adults with acquired brain injury, and make it easier for people to access these services.

Brain and Spine Foundation

3.36 Canterbury Court, Kennington Park,

1-3 Brixton Road

London SW9 6DE

Phone: 020 7793 5900 • Fax: 020 7793 5939

Website: www.brainandspine.org.uk • Email: info@brainandspine.org.uk

Brain and Spine Helpline

0808 808 1000 • Fax: 020 7793 5939

Email: helpline@brainandspine.org.uk

The Brain and Spine Foundation develops research, education and information program focusing on prevention, treatment and care of people affected by disorders of the brain and spine.

Headway - The Brain Injury Association

Scotland Office, Astley Ainslie Hospital

Canaan Lane

Edinburgh EH9 2HL

Phone: 0131 537 9116 • Helpline: 0808 800 2244

Website: www.headway.org.uk • Email: office@edinburgh.org.uk

Headway is a charity set up to give help and support to people affected by a head injury. A network of local groups throughout the UK offers a range of services including rehabilitation programmes, carer support, community outreach and respite care. Headway also provides a wide range of free information and fact sheets on many of the symptoms and practical issues associated with a brain injury. You can download these from the Headway website.

Health and Social Care Alliance Scotland

Venlaw Building

349 Bath Street, Glasgow G2 4AA

Phone: 0141 404 0231 • Fax: 0141 246 0348

Website: www.alliance-scotland.org.uk • Email: info@alliance-scotland.org.uk

Health and Social Care Alliance Scotland represents the two million people who live with long-term conditions in Scotland. It has members drawn from over 250 organisations and acts as a link between these groups, the people they represent and main stakeholders (people with an interest) across government services.

Momentum Head Office

Pavilion 7, Watermark Park
325 Govan Road
Glasgow G51 2SE

Phone: 0141 419 5299 • Fax: 0141 419 0821

Website: www.momentumscotland.org • Email: headoffice@momentum.org

Momentum is a voluntary organisation offering rehabilitation, training and care services for disabled people, including those who have had a brain injury.

Scottish Head Injury Forum (SHIF)

SHIF, c/o Charles Bell Pavilion, Astley Ainslie Hospital
133 Grange Loan
Edinburgh EH9 2HL

Website: www.shif.org.uk • Email: scottishhif@aol.co.uk

SHIF is a registered Scottish charity that organises training events aimed at professionals with limited specialist knowledge of brain injury but who treat or work with people who have had a brain injury as part of their job.

Scottish National Disability Information Service

Update, Hays Community Business Centre, 4 Hay Avenue
Edinburgh EH16 4AQ

Phone: 0131 669 1600

Website: www.update.org.uk • Email: info@update.org.uk

The Scottish National Disability Information Service offers a range of disability information including information about equipment, transport, holidays, benefits and where to get help and advice locally.

Other national organisations

Carers Scotland

The Cottage, 21 Pearce Street
Glasgow G51 3UT

Phone: 0141 445 3070

Website: www.carersuk.org/scotland

Carers Scotland provides information and advice to carers on all aspects of caring.

Contact a Family - Scotland

Craigmillar Social Enterprise and Arts Centre
11/9 Harewood Road
Edinburgh EH16 4NT

Phone: 0131 659 2930 • Helpline: 0808 808 3555 • Textphone: 0808 808 3556

Email: helpline@cafamily.org.uk

Website: www.cafamily.org.uk • Email: scotland.office@cafamily.org.uk

Contact a Family is a charity which provides support, information and advice to families of children and young people with a disability or health condition.

Crossroads Caring Scotland

24 George Square
Glasgow G2 1EG

Phone: 0141 226 3793

Website: www.crossroads-scotland.co.uk

Crossroads provides practical support to carers.

Princess Royal Trust for Carers in Scotland

Charles Oakley House, 125 West Regent Street

Glasgow G2 2SD

Phone: 0141 221 5066 • Fax: 0141 221 4623

Website: www.carers.org • Email: info@carers.org

The Princess Royal Trust for Carers in Scotland works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental-health or addiction problems.

What is SIGN?

We at the Scottish Intercollegiate Guidelines Network (SIGN) write guidelines which give advice to healthcare professionals, patients and carers about the best treatments that are available.

We write these guidelines by working with healthcare professionals, other NHS staff, patients, carers and members of the public.

The guidelines are based on the most up-to-date scientific evidence. You can read more about us by visiting www.sign.ac.uk or you can phone and ask for a copy of our booklet 'SIGN guidelines: information for patients, carers and the public'.

If you would like a copy of this booklet in another language or format such as in large print, please phone Karen Graham, Patient Involvement Officer, on 0131 623 4740, or email her at karen.graham2@nhs.net.

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The Healthcare Environment Inspectorate, the Scottish Health Council, the Scottish Health Technologies Group, the Scottish Intercollegiate Guidelines Network (SIGN) and the Scottish Medicines Consortium are key components of our organisation.



www.sign.ac.uk