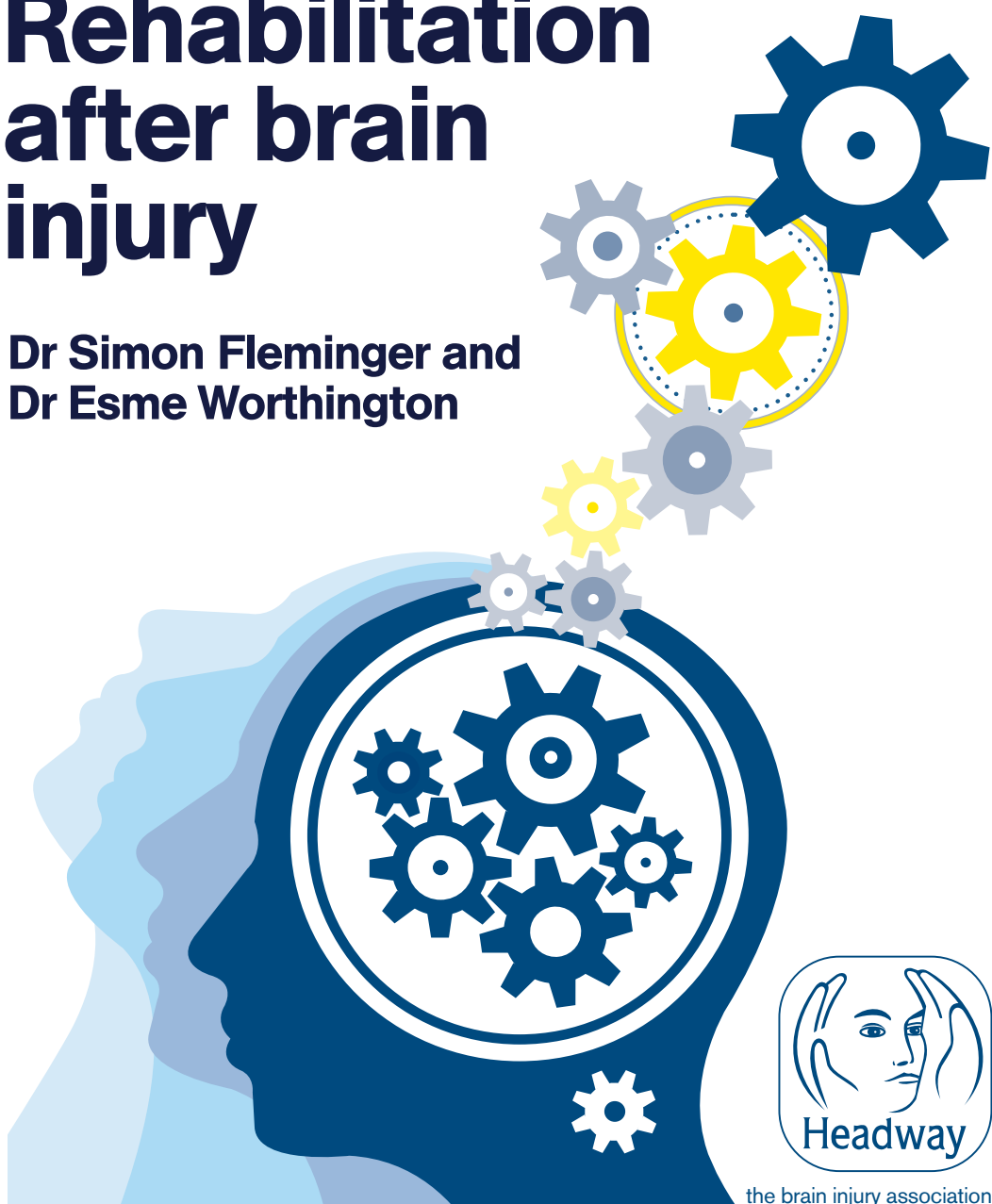


Rehabilitation after brain injury

Dr Simon Fleminger and
Dr Esme Worthington



the brain injury association

This booklet has been written as a guide to brain injury rehabilitation, its settings, aims and the professionals involved. It is intended primarily for the families and carers of brain injury survivors.

■ Rehabilitation after brain injury

This e-booklet is an adaptation, created in September 2016, of the Headway print booklet *Rehabilitation after brain injury* and may contain minor updates to the original version.

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Introduction

 Once a person with a brain injury is medically stable and any physical injuries have been treated, they may be ready to be discharged from the hospital, or 'acute care', setting. However, many of these individuals are likely to experience complex, longer-term **physical, cognitive and behavioural problems**, which require a period of rehabilitation.

Unlike most other cells in the body, brain cells do not regenerate when they are destroyed. However, this does not mean that no recovery can occur. The brain is somewhat flexible and is able to reorganise itself, to an extent, in order to regain lost function. This is known as brain *plasticity*. During recovery, other areas of the brain take over the activities of the damaged areas and new nerve pathways can be established using undamaged 'spare' brain cells. Engaging in activity helps these alternative pathways to develop.

Rehabilitation aims to help the brain learn alternative ways of working in order to minimise the long-term impact of the brain injury. Rehabilitation also helps the survivor and the family to cope successfully with any remaining disabilities.

Accessing rehabilitation



There are many rehabilitation services across the UK, run by the NHS or private firms. Choosing which rehabilitation unit to refer someone with a brain injury to should involve the clinical team, the patient and their family. Once a referral has been made, the rehabilitation unit will usually carry out an assessment to make sure their service is suitable.

Availability and funding for places varies. However, most units, including private ones, accept NHS referrals and will be funded by the NHS. Other possible sources of funding include local authority social services, medical insurance, compensation claims and self-funding.

It is important to ensure that whoever is likely to have to fund the rehabilitation is aware that a referral has been made. The rehabilitation service will not be able to accept an admission until funding has been authorised. Many services accept referrals from outside their own area, but there are often limited places available and long waiting lists. Specific details about the referral process, funding options and availability of places will be available from the unit.

Taking up a rehabilitation placement is an important commitment, and it is wise to explore all the options, visit different rehabilitation settings, and ask as many questions as possible before a placement is confirmed.

Rehabilitation settings



Rehabilitation occurs in the following settings. Most rehabilitation units provide one or more of these services:

Post-acute rehabilitation: Intensive specialist rehabilitation for people who are not yet ready to return home after discharge from hospital. Neurological rehabilitation centres provide an ideal setting for further treatment, with a structured rehabilitation programme in place throughout the day.

Rehabilitation back into the community: Following an inpatient rehabilitation stay, some patients may be transferred to a residential transitional living unit. Here the patient will develop their independent living skills so that when they leave they are able to live in a place of their own. Other patients will go straight back to their homes, with community rehabilitation teams or outreach teams helping them to make further progress; this may involve therapists coming to visit the person in their home or hostel.

Outpatient rehabilitation: Some patients may be well enough to return home and receive further treatment as an outpatient, either at a local hospital or at a separate rehabilitation centre.

Slow-stream rehabilitation: Some patients who no longer require intensive post-acute rehabilitation may still not be ready to return home. These people may require long-term residential care.

Severely injured patients may still have the potential to make continued progress, even several years after the injury, although this may be slow. Therefore, it is important that their

rehabilitation is not cut short. Many brain injury residential care units provide what is known as ‘slow-stream rehabilitation’ and if somebody with a brain injury can potentially benefit from this approach it is important they are given the opportunity.

All residential care services should be registered with the [Care Quality Commission \(CQC\)](#). You can check whether a particular unit is registered and view reports on the service by contacting the CQC on **03000 616161**, or by visiting their website.

What if no rehabilitation has been provided?


If your relative has been discharged home without any access to rehabilitation, and you have reason to believe that they would benefit from it, there are still options available.

You 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 contact rehabilitation services directly. The [Headway helpline](#) can provide information on specialist brain injury rehabilitation centres across the UK. For further information, call the helpline on **0808 800 2244**.

You can find a directory of rehabilitation services across the UK on the [Brain Nav – The National Brain Injury Service Directory](#) website. It is advisable to contact several units and visit them to assess their suitability before making a decision.

Timescales for recovery and rehabilitation



In the first month or two after a severe brain injury it is only possible to guess at the length of time that recovery will take and the likely outcome. All that is certain is that recovery is a slow process and will take months or years rather than weeks.

Six months after the injury the picture will be clearer, but it is wise to wait until about a year after the accident before making any important decisions regarding the future. After a year or so one can be reasonably certain about the eventual degree of *physical* recovery. However, *psychological* recovery can take considerably longer and it is usually the **cognitive (thinking)**, **emotional** and **behavioural problems** that cause longer-term difficulties, particularly for family members.

People do sometimes talk about there being a limited 'window' for recovery after brain injury, for example, that recovery ceases to take place beyond two years. 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 the injury.

Nevertheless, the greatest visible progress does occur in the first six months or so post-injury and after this improvement is often less obvious.

Factors which may affect the rate of the person's recovery include:

- Type, severity and location of the person's brain injury
- Age (younger adults tend to do better)
- Pre-injury health
- Pre-injury personality, intelligence and lifestyle
- Social support from family and friends
- Other issues, such as alcohol or drug misuse.


Depending on the individual's specific difficulties and their potential for recovery as assessed by rehabilitation staff, a programme of rehabilitation may last for a few weeks or may continue for months or years.

Headway Approved Provider scheme

Headway has developed the Approved Provider scheme, an accreditation scheme appropriate for NHS and independent care settings, including hospitals and neuro-rehabilitation units, residential care homes, nursing homes and respite facilities specialising in ABI.

The units on the [Approved Provider list](#) have been assessed against standards devised by Headway to ensure they provide appropriate specialist care for brain injury survivors with complex physical and cognitive impairment. Further information and a list of Approved Providers can be accessed on the [Headway website](#).

The rehabilitation team



In a specialist rehabilitation setting, a 'multidisciplinary' team of professionals will work closely with the person with a brain injury.

Initially, each therapist will carry out detailed assessments to explore the extent of the difficulties caused by the brain injury, including **physical, cognitive, emotional, behavioural** and social difficulties.

Following the assessment process, the team will discuss with the client and the family what their priorities and goals for the period ahead might be and what they hope to achieve. Based on this, the rehabilitation goals – both short and long-term – will be agreed and the rehabilitation programme will be planned. In devising the rehabilitation programme, the team will want to set goals that take into account each patient's individual views and needs, their cultural background, and pre-injury lifestyle and interests.

The different therapists who may be involved in the rehabilitation process, and their areas of expertise, are outlined below:

Clinical neuropsychologist

A clinical neuropsychologist is a psychologist who specialises in the assessment and treatment of behavioural, emotional and cognitive (thinking) problems following brain injury. A neuropsychologist can advise on how to build upon the person's existing skills and abilities and how to reduce some of their difficulties.

Occupational therapist (OT)

OTs help people to develop independence in carrying out daily tasks such as dressing, washing, cooking and leisure activities. An OT will also help the person to develop the skills that underlie these activities, such as budgeting and planning, and help to find ways around any remaining problems. At a later stage, the OT may help and advise on difficulties that may be encountered in the home environment and advise on any adaptations that may need to be made. They will also be involved in planning for returning to work. There are OTs working within both the NHS and social services.

Speech and language therapist

A speech and language therapist (sometimes referred to as a SALT or SLT) helps people to improve their communication skills. This may include understanding and expressing both written and spoken language and improving speech clarity. The speech and language therapist will work with family members to help the person to communicate as best they can in their daily life and will identify any communication aids that may be helpful. They may also be required to assess swallowing difficulties and provide guidance on how this should be managed safely.

Further information on this subject can be found in the Headway booklet *Coping with communication problems after brain injury*.

Physiotherapist

A physiotherapist helps people to regain the use of their muscles and joints after injury and helps with balance and

movement problems. A 'physio' will, for example, suggest exercises to help the person improve their physical ability and enable them to become as mobile and independent as possible.

Nurse

Nurses help the therapists to implement many of the rehabilitation strategies. In many in-patient rehabilitation units the care provided by the nursing team is the foundation for the rehabilitation programme provided by the multidisciplinary team. On in-patient units and in the community there may be specialist nurses who take on specific roles, such as the management of epilepsy or behavioural programmes.

Social worker

Social workers provide practical advice on issues such as benefits, housing, transport and assistance at home. They are also trained to offer emotional support to individuals and their families.

Case manager

A case manager is responsible for overseeing and managing the overall care of the person with a brain injury. They will prepare an individually-tailored care plan or treatment programme for each client, which is designed to meet the person's specific health, social and emotional needs. Case managers can come from a variety of professional backgrounds, such as social work, occupational therapy, or nursing. Brain injury case managers are usually only available through private referrals and interim compensation payments.


Family members

Family members have a very important role to play in helping the survivor make as full a recovery as possible. A good working relationship between the family and the rehabilitation team is essential in making sure that rehabilitation programmes are followed correctly. Research suggests that the patients who make the best recovery are those whose family is actively involved and can maintain the skills learned in rehabilitation once the patient has gone home.

Sometimes relatives will need to learn new skills so that they can help to provide the best support. However, it is important that the family member does not become a 'therapist' and that they are encouraged to focus primarily on their role as somebody who provides love and affection. Family members are usually invited to participate in formal meetings with staff members to keep them informed of their relative's progress. Sometimes the family will need to act as an advocate for the survivor when the survivor lacks the capacity to make decisions for themselves.

There are many rehabilitation professionals working in private practice. If little or no rehabilitation has been provided by the NHS or social services then one option can be to contact professionals independently. It may still be possible to obtain an NHS or social services referral, or it may be necessary to pay privately. You can find details of organisations who provide directories of chartered rehabilitation professionals in private practice in the '[Useful organisations](#)' section at the back of the booklet.

Psychological recovery




A wide variety of [cognitive, behavioural and emotional](#) problems can occur after brain injury and may impact significantly on work and family relationships. Even after minor injury some people have persistent problems for months or even years.

Problems may not be immediately obvious after the injury, but may become apparent some weeks or months later as the person engages in more activities. Nevertheless, particularly for those with severe injuries, slow but steady improvement tends to occur in psychological symptoms over a period of months or years.

Many cognitive, behavioural and emotional problems can be helped by treatment from a [clinical neuropsychologist](#). For example, if problematic behaviours develop after brain injury (such as verbal or physical aggression, or inappropriate sexual behaviour) **behavioural modification programmes** may be used to raise the patient's awareness of their behaviours and encourage more appropriate responses. **Cognitive rehabilitation** may also be used to help improve attention, memory, and language abilities. Finally, various psychotherapy approaches may also be used, such as **cognitive behavioural therapy (CBT)**, which help patients to learn to cope emotionally with their disabilities and to re-establish meaning in their life.

There are a number of [publications](#) available from Headway that give detailed information on psychological difficulties after brain injury. See 'Further reading' for more information.

Returning to work



Once the person is able to look after their personal needs, to travel around from place to place and to manage social contacts reasonably well, they may be able to consider **returning to work**. This will depend largely on the degree of recovery that has been made, what the person's previous job was and what employment opportunities may now be available. For those with less severe injuries, return to work within a few weeks or months is often achievable.

However, it is important not to rush back to work too quickly. If this happens, some problems that had seemed to be resolved may reappear. The person may, for example, suddenly find that their concentration or energy levels, which seemed fine at home when convalescing, are not as good as they thought. It is often wise to look at a phased return to work, so that the way in which the person is coping with the transition can be gently tested out. Some people will be able to return to their old job, while others may need to consider a less demanding role. A period of retraining may be required and adaptations to the workplace may be needed.


Ideally, a specialist brain injury vocational rehabilitation service will be able to provide assessment and rehabilitation programmes that will enhance the potential to return to work. Vocational rehabilitation involves professionals such as neuropsychologists and occupational therapists, who can help people to understand the type of work they can now do and support them to achieve their goals.

Only a small number of specialist vocational rehabilitation services are available, although many units and community brain injury teams provide similar services. The [Headway website](#) provides details of the services available in the UK and the information in the ‘[Accessing rehabilitation](#)’ and ‘[What if no rehabilitation has been provided?](#)’ sections of this booklet also applies to these services.

If the injury has been very severe, the person may not be able to return to paid employment. In this case, it is important that a plan is worked out to give the person a regular, satisfying way of spending their time. Access to leisure activities, social interactions and other meaningful activities such as volunteering will be important to provide structure in their life, as well as a sense of purpose and achievement. Local [Headway groups and branches](#), as well as social services day centres and other voluntary and statutory sector organisations, may be able to provide facilities to accommodate these needs.

For further information on returning to work, including a range of freely downloadable factsheets, visit the [website](#).

Support for families




The various difficulties that can occur after brain injury, in particular behavioural and emotional problems, can have a big impact on family members. There may well be additional social or financial difficulties for the family, and relatives may need as much help and support as possible.

Studies have shown that family support and counselling are needed, not just in the early days but for a long time afterwards. The children of a brain injured parent can also be easily overlooked. It is very important that the relatives acknowledge the difficulties they are experiencing and ask for help when they need it.

The GP is normally the first point of contact, who, in turn, may advise seeking help from a clinical psychologist, social worker, counsellor, or others as appropriate and available. Local Headway groups and the Headway freephone helpline can also be useful in supporting both the person with the injury and their relatives and friends. (See contact details for Headway on the inside back cover).

Further reading


 The following books are available from Headway and provide a good introduction to brain injury and its effects:

- Clare, L. & Wilson, B.A. (1997) *Coping with Memory Problems: A practical guide for people with memory impairments, their relatives, friends and carers.* London: Pearson Assessment.
- Daisley, A., Tams, R. and Kischka, U. (2008) *Head Injury: The Facts.* Oxford: Oxford University Press.
- Hedley, N (2011) *Living with an Acquired Brain Injury: The Practical Life Skills Workbook.* Milton Keynes: Speechmark Publishing Ltd.
- Johnson, J. (2013) *My Dad Makes the Best Boats.* Milton Keynes: Speechmark Publishing Ltd.
- Johnson, J. (2013) *My Mum Makes the Best Cakes.* Milton Keynes: Speechmark Publishing Ltd.
- Johnson, J. (2011) *"My Parent has a Brain Injury..." ...a Guide for Young People.* Self-published.
- Powell, T (2013) *The Brain Injury Workbook: Exercises for Cognitive Rehabilitation.* Milton Keynes: Speechmark Publishing Ltd.
- Powell, T. (2004) *Head Injury: A Practical Guide.* Milton Keynes: Speechmark Publishing Ltd.

Headway also produces an extensive range of booklets and freely downloadable e-booklets and factsheets. For more information, please visit our website at **www.headway.org.uk/information-library**, or telephone **0115 924 0800**. Brain injury survivors and carers can receive free print copies of appropriate booklets from the Headway helpline on **0808 800 2244**.

Headway's Amazon shop sells a wide range of books on the subject of brain injury and brain function. Visit **astore.amazon.co.uk/headwathebrai-21**

Clinical guidelines



The following guidelines have been produced in order to improve rehabilitation services for adults with acquired brain injury and their families and carers.

- British Society of Rehabilitation Medicine (2009). *BSRM Standards for Rehabilitation Services, Mapped onto the National Service Framework for Long-Term Conditions*. London: BSRM, 2009.
- Royal College of Physicians and British Society of Rehabilitation Medicine. *Rehabilitation following acquired brain injury: national clinical guidelines* (Turner-Stokes, L., ed). London: RCP, BSRM, 2003.
- Royal College of Physicians, British Society of Rehabilitation Medicine and Department for Work and Pensions. *Vocational assessment and rehabilitation after acquired brain injury: inter-agency guidelines* (Tyerman, A. & Meehan, M., eds). London: RCP, BSRM, 2004.

The first report listed is available to download free of charge from the British Society of Rehabilitation Medicine's website at **www.bsrn.co.uk**. Go to the 'Publications' section.

The other two reports are available to download free of charge from the Royal College of Physicians (RCP) website at **www.rcplondon.ac.uk**. Go to the 'Shop' section, click on 'Explore our bookshop' and search the A-Z list.

Useful organisations

Afasic

Helpline: 0300 666 9410

Web: www.afasic.org.uk

ASSIST Trauma Care

Helpline: 01788 560 800

Web: www.assisttraumacare.org.uk

Brain and Spinal Injury Charity (BASIC)

Helpline: 0870 750 0000

Email: enquiries@basiccharity.org.uk

Web: www.basiccharity.org.uk

Brain and Spine Foundation

Helpline: 0808 808 1000

Email: helpline@brainandspine.org.uk

Web: www.brainandspine.org.uk

Brain Tumour Charity, The

Helpline: 0808 800 0004

Email: support@thebraintumourcharity.org

thebraintumourcharity.org

Web: www.thebraintumourcharity.org

Carers UK

Helpline: 0808 808 7777

Email: advice@carersuk.org

Web: www.carersuk.org

Cerebra

Helpline: 0800 328 1159

Email: info@cerebra.org.uk

Web: www.cerebra.org.uk

Child Brain Injury Trust

Helpline: 0303 303 2248

Email: helpline@cbituk.org

Web: www.childbraininjurytrust.org.uk

Connect – the communication disability network

Tel: 020 7367 0840

Email: info@ukconnect.org

Web: www.ukconnect.org

Different Strokes

Helpline: 0845 130 7172

Email: info@differentstrokes.co.uk

Web: www.differentstrokes.co.uk

Encephalitis Society

Helpline: 01653 699 599

Web: www.encephalitis.info

Epilepsy Action

Helpline: 0808 800 5050

Email: helpline@epilepsy.org.uk

Web: www.epilepsy.org.uk

Epilepsy Society

Helpline: 01494 601 400

Web: www.epilepsysociety.org.uk

Meningitis Now

Helpline: 0808 80 10 388

Email: info@meningitisnow.org

Web: www.meningitisnow.org

Meningitis Research Foundation

Helpline (24hr): 0808 800 3344

Email: info@meningitis.org

Web: www.meningitis.org

Pituitary Foundation, The

Helpline: 0845 450 0375

Email: helpline@pituitary.org.uk

Web: www.pituitary.org.uk

Stroke Association

Helpline: 0303 3033 100

Email: info@stroke.org.uk

Web: www.stroke.org.uk

Rehabilitation and counselling services

The following organisations provide information on rehabilitation, care homes or counselling services in the UK. Some have online directories of professionals in NHS or private practice. Headway does not recommend any specific services and it is suggested that you contact more than one before making a decision.

Association for the Rehabilitation of Communication and Oral Skills (ARCOS)

Helpline: 01684 576 795

Email: admin@arcos.org.uk

Web: www.arcos.org.uk

Association of Speech and Language Therapists in Independent Practice

Tel: 01494 488 306

Web: www.helpwithtalking.com

BrainNav – The National Brain Injury Service Directory

Web: www.brainnav.info

British Association for Behavioural and Cognitive Psychotherapies (BABCP)

Tel: 0161 705 4304

Email: babcp@babcp.com

Web: www.babcp.com

British Association for Counselling and Psychotherapy

Tel: 01455 883 300

Email: bacp@bacp.co.uk

Web: www.bacp.co.uk

British Association of Brain Injury Case Managers (BABICM)

Tel: 0161 764 0602

Email: secretary@babicm.org

Web: www.babicm.org

British Association of Occupational Therapists and College of Occupational Therapists

Tel: 020 7357 6480

Email: reception@cot.co.uk

Web: www.cot.co.uk

British Psychological Society (BPS)

Tel: 0116 254 9568

Email: enquiries@bps.org.uk

Web: www.bps.org.uk

Care Quality Commission (CQC)

Tel: 03000 616161

Web: www.cqc.org.uk

Chartered Society of Physiotherapy

Tel: 020 7306 6666

Web: www.csp.org.uk

College of Sexual and Relationship Therapists

Tel: 020 8543 2707

Email: info@cosrt.org.uk

Web: www.cosrt.org.uk

Counselling Directory

Tel: 0333 3447 990

Web: www.counsellingdirectory.org.uk

UK Council for Psychotherapy

Tel: 020 7014 9955

Email: info@ukcp.org.uk

Web: www.ukcp.org.uk

Physio First

Tel: 01604 684 960

Email: minerva@physiofirst.org.uk

Web: www.physiofirst.org.uk

Relate – the relationship people

Tel: 0300 100 1234

Web: www.relate.org.uk

Royal College of Speech and Language Therapists (RCSLT)

Tel: 020 7378 1200

Email: info@rcslt.org

Web: www.rcslt.org

UK Council for Psychotherapy

Tel: 020 7014 9955

Email: info@ukcp.org.uk

Web: www.psychotherapy.org.uk

United Kingdom Acquired Brain Injury Forum (UKABIF)

Tel: 0845 608 0788

Email: info@ukabif.org.uk

Web: www.ukabif.org.uk

How to donate

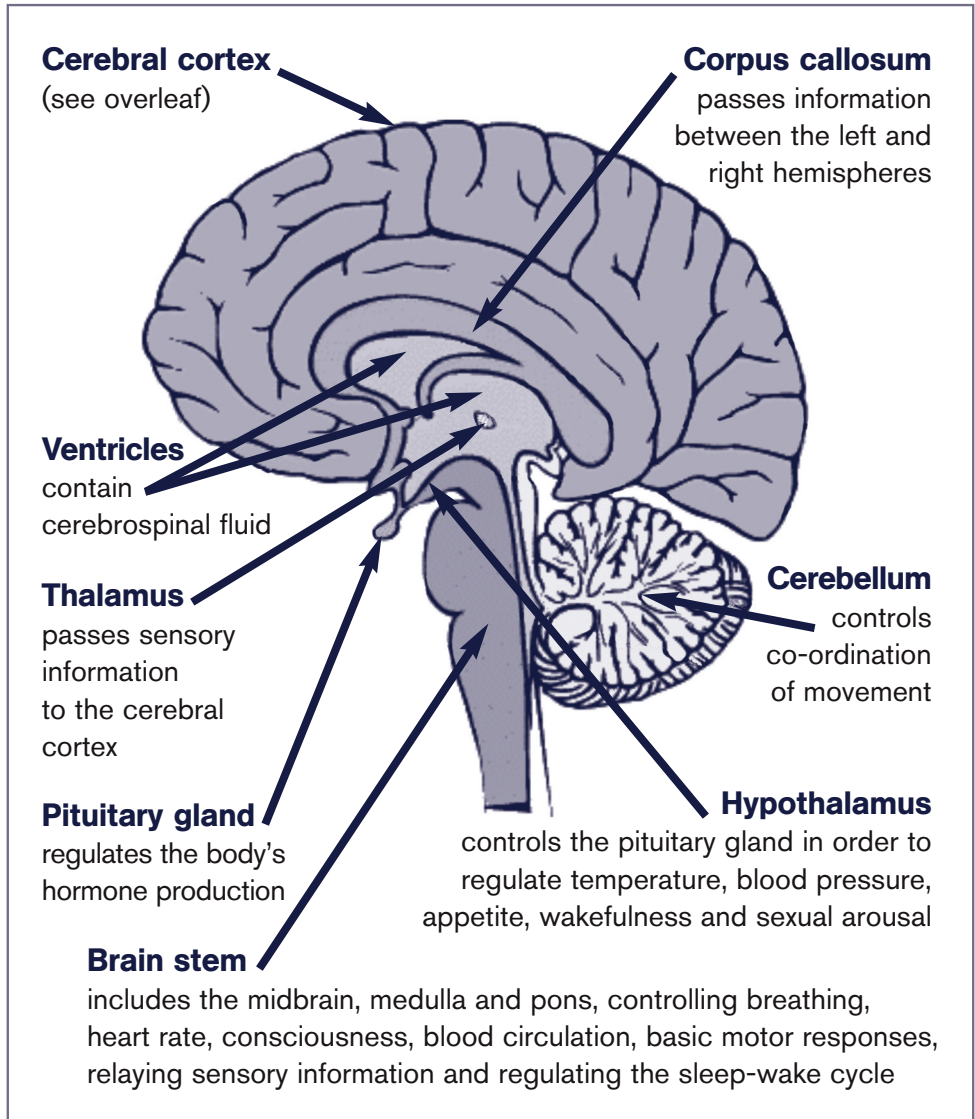


Headway – the brain injury association is a registered charity (1025852) and relies upon voluntary support to fund its work.

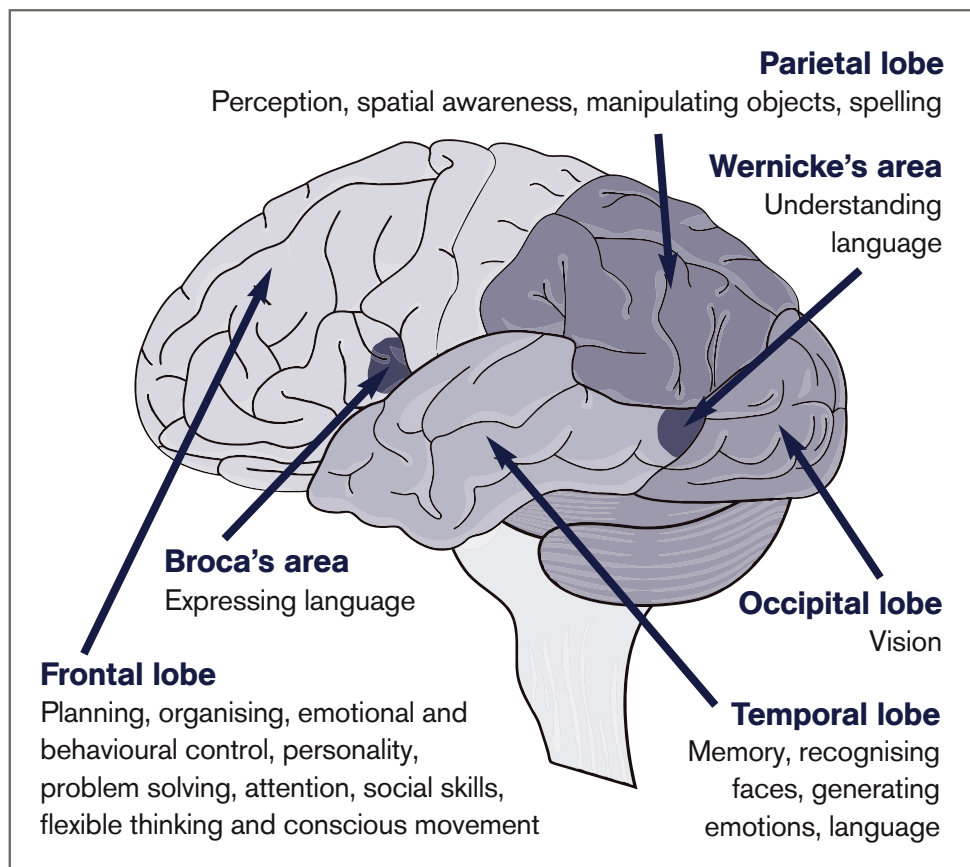
If you would like to help Headway by making a donation you can do so by donating online at **www.headway.org.uk**, contacting the Fundraising Team on **0115 924 0800**, or sending a cheque to:

Headway – the brain injury association
Bradbury House
190 Bagnall Road
Old Basford
Nottingham NG6 8SF


Internal areas of the brain and their function



The cerebral cortex



About Headway



Headway – the brain injury association is a charity set up to give help and support to people affected by brain injury.

A network of local Headway groups and branches throughout the UK offers a wide range of services including rehabilitation programmes, carer support, social re-integration, community outreach and respite care. The Headway helpline provides information, signposts to sources of support and rehabilitation services, and offers a listening ear to those experiencing problems. Other services provided by Headway include:

- Supporting and developing local groups and branches
 - Promoting understanding of brain injury and its effects
 - An award-winning range of publications on aspects of brain injury
 - Accreditation of UK care providers through the Approved Provider scheme
 - A comprehensive, award-winning website
 - Campaigning for measures that will reduce the incidence of brain injury
 - Providing grants from our Emergency Fund for families coping with financial difficulties
 - Headway Acute Trauma Support (HATS) nurses to support families with loved ones in hospital
- Freephone helpline: 0808 800 2244
(Monday–Friday, 9am–5pm)
- Telephone: 0115 924 0800
- Website: www.headway.org.uk
- Fax: 0115 958 4446
- Email: helpline@headway.org.uk



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