

Caring for someone with a brain injury

Richard Morris



the brain injury association

This booklet has been written for the carers and family members of people with a brain injury. It provides practical suggestions to help you to cope with the early stages, manage the long-term challenges and find the support you need.

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Headway information and support

If you wish to talk to someone about any of the information in this booklet, contact the [Headway helpline](tel:08088002244) on **0808 800 2244** or helpline@headway.org.uk (Monday – Friday, 9am-5pm). The helpline can offer information about brain injury and a listening ear if you need emotional support. They can also send out limited free copies of [publications](#) and provide details of Headway groups and branches.



This booklet received a Highly Commended award at the British Medical Association Patient Information Awards 2011.

Introduction



This booklet has been written for the carers and family members of people with a brain injury. If you are caring for someone with a brain injury, or have a relative being treated in hospital, then the information should help you to meet the challenges ahead and find the support you need.

Brain injury doesn't just affect individuals; it can transform the lives of entire families. Depending upon the severity of your relative's injury and its effects, you may have to make considerable changes to the way you live, such as becoming a part-time or full-time carer. This booklet provides practical suggestions to help you cope with the early stages and manage in the long-term if it becomes necessary.

The subject of brain injury is very complicated with many different issues involved, some of which go beyond the scope of this booklet. Therefore, there are a number of subjects we have not covered here, including:

- Detailed information on all possible effects of brain injury
- Issues when the person with a brain injury is in a coma
- Issues involving children with a brain injury.

There are a wide variety of other sources of information on these and other important subjects, some of which are provided by Headway. The booklet will signpost you to other information where appropriate and the '[Further reading](#)' and '[Useful organisations](#)' sections provide further helpful resources.

Section one: The early stages after injury

The period immediately following your relative's brain injury is a frightening and confusing time. The outcome can be very uncertain and it will probably be the first time you will have had any experience of brain injury. It is important to access information and support as early as possible. If your relative was recently injured then we hope the information in this section will help you to start making sense of the situation.

Understanding hospital systems

The treatment pathways for different kinds of acquired brain injury vary. In the case of very serious injuries, a person will normally be taken to the local Emergency Department, where they will be assessed and their condition stabilised. They should then be transferred to a neurological centre, if it is considered appropriate and there are beds available. If not, they will be admitted to a general hospital and may be treated on a non-specialist ward.

It is very important after brain injury that your relative rapidly receives the best specialist care possible. If the treatment is provided in a general hospital then the doctors there should consult with neurologists and neurosurgeons at a nearby neurological centre.

It is worth remembering that, on many occasions, people with minor brain injury may not spend any time in hospital and

consequently don't get referred to appropriate rehabilitation and support services.

Coping with the hospital stage

After a brain injury, the stay in hospital is often far more distressing for family and friends than it is for the person with the injury, who may be unconscious or have no awareness or memory of this period.

Your main concern at this time will be the well-being of your relative, but you should also remember that the best way to help is to look after yourself and you shouldn't neglect your own well-being.

A carer's story

After my mum sustained a brain injury I had to cope with significant changes in my life. I found myself taking on many caring duties and also helping my dad to manage with household chores like cleaning, shopping, washing and ironing. Often this was really stressful, as I not only had to cope with the changes in my mum's personality, but I also found myself constantly worrying about my dad and how he would manage if I left home. This meant it was difficult for me to pursue interests in my own life such as work and leisure opportunities.

Sharing my feelings with family and friends helped me to cope with the situation and I also found that taking some time for myself and doing the things I enjoyed, such as running and cycling, helped me to feel much more positive about myself and the changes that had occurred to my family.

Roberta

You will probably want definite answers in the early stages, which the medical staff often can't provide. Rest assured that, if this is the case, you are not being deliberately kept in the dark. If the injury is very severe then stabilising and managing your relative's condition will be the main priority.

The long-term difficulties will only become apparent at a later stage, such as when rehabilitation starts, or even when they return home.

In the early stages it really is a matter of taking each day as it comes. It is important to ask the consultants questions, but try not to feel too frustrated if they don't have all the answers.

What you can do to help your relative

It is normal to feel quite helpless when your relative is in hospital and to feel desperate to be able to do something constructive. There are many factors involved in the treatment of different kinds of brain injuries so we can't advise on specific activities here, as some things may be beneficial in some instances but harmful in others. Helping your relative can take many forms and the following can all make valuable contributions:

- Communicate as much as possible with the medical staff. They will be able to suggest any appropriate ways for you to help.
- Organise visiting hours with family and friends, so that you provide adequate support for your relative, without overwhelming them or causing any disruption to their treatment and recovery.

- Provide interest and stimulation. Just talking to your relative about everyday things can help, as does providing books, magazines, DVDs, etc.
- Help with personal care and grooming under the advice and supervision of nursing staff.
- Try to arrange the week's tasks at the start of the week so you can stay organised and don't have to keep asking the staff.

What you can do to help yourself

This is a time during which you will probably have to do a great deal of reorganisation in your daily life and it is very important to remember to look after yourself.

The following advice is worth keeping in mind:

Lean on others

- Seek help from professionals, such as hospital staff, the Patient Advice and Liaison Service (PALS; see [page 13](#)) and your GP.
- Be very clear and assertive in telling people in authority what you want and what you need from them.
- Seek the help and support of relatives, friends and neighbours.
- Involve all of the family in taking on household tasks.
- Ask one particular person in the family to deal with any enquiries from concerned relatives and friends, since this can be particularly stressful.
- Be aware of other sources of support at the hospital, such as the chaplaincy or other sources of religious guidance.
- Talk to other families on the ward in similar situations.
- Ask to see a hospital social worker.

Rest, take breaks and make time for yourself

- Do not feel that you or members of your family have to spend 24 hours a day sitting at your relative's bedside. You will cope best if you are able to go home for a while and get as much sleep and rest as possible.
- If you are having a lot of trouble sleeping, speak to your GP who will be able to discuss relaxation techniques, therapy, medication, or referral to counselling.
- Try to make time for activities that you find enjoyable, such as hobbies and socialising with friends.

A carer's story

I found it really tiring when Dad was in hospital; being there all the time, making sure I was always there in case the consultants came round or I missed movements or changes in his behaviour.

*Family and friends said they would sit with him so I could take some time for myself, but I was still anxious about this. They bought a large diary to put by his bed and wrote down anything he did, any movements, eye opening, what the nurses did and said, even small things. This provided the reassurance I needed and allowed me to take some time out. It also proved really useful when the consultants did come round so we could discuss any changes with them. **Debbie***

Make financial arrangements

- Talk things through with your bank manager in order to reschedule any debts and budget for your new circumstances.
- Organise personal finances and payment of bills. This can be a particular problem if your relative was previously responsible. If possible, arrange for a willing and responsible friend or family member to take on the duty. Alternatively, contact your local Citizens Advice for advice on local sources of support.

- Seek advice on the benefits you and your relative may be entitled to. If your relative was on benefits before going into hospital then these may be affected. For more information on benefits, see the Headway booklet *A guide to welfare benefits after brain injury*.
- Check any insurance policy your relative has, particularly medical insurance.
- Talk to your relative's employer to find out if they have an occupational pension which is initiated following serious injury.
- If your relative has been in an accident you may be able to take legal action against the person or organisation responsible. It is important to seek advice from a solicitor with expertise in brain injury claims. See the Headway booklets *Claiming compensation after brain injury* and *Claiming compensation in Scotland after brain injury* for more information. You can find Headway's directory of head injury solicitors at www.headway.org.uk/supporting-you/in-your-area

Make arrangements with employers

- Keep both your own and your relative's employers informed about the situation and make sure that arrangements are in place regarding time off and statutory sick pay.
- Check whether your employer has a scheme for compassionate leave. Your contract of employment or company handbook should contain details of this.
- If your contract has no provision for compassionate leave then your employer has no legal obligation to grant you time off, so it is especially important to be as communicative as possible with your employer in order to help them understand your situation.
- Your relative will be entitled to a minimum of 28 weeks statutory sick pay, or more if allowed in their employment

policy. For the employer to consider dismissal, they must have excellent medical grounds to say your relative will not be capable of returning to the job in any capacity.

- A good point of contact if you have any concerns about employment matters is the [Advisory, Conciliation and Arbitration Service \(ACAS\)](#). You can contact their confidential helpline on **0300 123 1100**.
- If your relative is self-employed you may need to check if they are insured for accidents or illness. If not then you will need to make arrangements to ensure that tax is paid and that any business associates or clients are informed of the situation. You might want to appoint a willing friend or family member to deal with these matters. The local [Citizens Advice](#) can offer assistance and signpost to local sources of support.

Keep records

- Try to keep records of events. This often proves to be useful at a later date as it can be very difficult to recall everything accurately if it isn't written down.
- Ask for a copy of any letters the hospital sends to your relative's GP. These can provide valuable supporting evidence for benefits and compensation claims.
- Keep notes of the date and time of the injury, the treatment your relative receives and the professionals who provide treatment and care.
- If possible arrange for a responsible friend or relative to keep these records on your behalf.

Look after your physical health

- It is important to remember to eat a healthy, balanced diet
- Make time for exercise
- See your GP with any health concerns of your own.

Understand and manage your emotional reactions

It is important to remember the following points:

- There is no right and wrong way to feel at a time like this and **ALL** reactions can be considered completely natural. Feelings such as shock, numbness, anxiety, fear, guilt, denial, anger and depression are all very common things to experience at this stage.
- Feelings change rapidly at this time and it can be impossible to predict the stages of your emotional reactions.
- Coming to terms with a relative's injury is a complex and ever-changing process and you may find yourself feeling emotions that you thought you had left behind.
- Don't expect everything to make sense initially. Speak to other carers and families who have been through a similar situation. Try to make time to speak to other families on the ward and make contact with your local [Headway group or branch](#) and the [Headway helpline](#).
- Try to keep returning to any written materials you have received. It will be difficult to take things in at first, but the information will gradually start to sink in.
- Your GP may be able to refer you to local counselling services. You can also find directories of counsellors in the '[Useful organisations](#)' section at the back of this booklet.

Children's emotional reactions and how to help

The issues facing young children can be particularly challenging. If you have children, or there are children in the family, these are some issues you might wish to consider.

- Children may find it harder than adults to understand changes in a relative's personality.

- Children may be particularly prone to blaming themselves for a close relative's injury.
- It can be particularly difficult for children to cope with role changes in the family.
- Children may experience bullying because of having a parent who is 'different'.
- Children are often not willing to openly discuss their problems and to seek help, so may try to cope by behaving in a problematic way.
- There are many different issues for children, depending on their age group and stage of development.

The information and support you offer to a child will depend on what is appropriate for their age and level of understanding. Some general suggestions include:

- Recognise and try to understand the way a child is affected.
- Educate them about the injury and its effects.
- Listen to them and try to involve them in decisions.
- Reassure them that their emotions, whatever they may be, are perfectly natural.
- Keep them informed about the situation. You may feel that you are protecting their feelings by keeping information from them, but this can just lead to them feeling isolated and confused.
- Remember, there is no single, correct way to help children. The most important thing is to have a willingness to talk to them and to listen to their concerns.
- Educate the child's teachers about the effects of brain injury.

It is important to try to access the right support for children and this can be difficult. Medical and rehabilitation staff may feel that they don't have the specific expertise to help children and teachers often have little or no knowledge of brain injury.

Sources of support that you can seek are:

- The GP will be able to refer to appropriate local services.
- It would be useful to have access to a clinical psychologist with expertise in brain injury and working with children.
- Child psychologists can be useful, although it would be particularly helpful to find one with specific knowledge of brain injury.
- If you are unable to obtain appropriate NHS referral, the British Psychological Society (BPS) website, at www.bps.org.uk, has a directory of chartered psychology services, including clinical and child psychologists.
- You can find out about educational psychology services from the child's school or by contacting the Local Education Authority.
- Special Educational Needs Co-ordinators (SENCOs) may be able to help or signpost to other sources of support. Again, the school will be able to give details.

More information on supporting children during this time is available in the Headway booklet *Supporting children when a parent has had a brain injury*.

NHS patient support services

The Patient Advice and Liaison Service (PALS) is a source of advice and support at every NHS hospital in England. PALS can help to deal with any concerns you have about your relative's treatment and help to arrange meetings with consultants.

You can find details at the hospital reception desk or website. Alternatively, you can search for a PALS service in your area on [the NHS Choices website](#). Other similar services are available elsewhere in the UK.

■ Caring for someone with a brain injury

In Scotland, contact the [Patient Advice and Support Service \(PASS\)](#) via your local Citizens Advice.

In Wales, the [Community Health Councils \(CHCs\)](#) can provide advice and support. You can contact your local service through the Board of Community Health Councils on **02920 235 558**, or enquiries@waleschc.org.uk.

The [Patient and Client Council \(PCC\)](#) in Northern Ireland offers support for concerns or complaints and you can discuss issues with their Patient and Client Support Officers (PCSOs). Contact them on **0800 917 0222**, or info.pcc@hscni.net.

For detailed information on making complaints about NHS services in the UK see the Headway factsheet [Making a complaint about health and social care services](#).

Headway Emergency Fund

The Headway Emergency Fund was established to help people cope with financial difficulties after brain injury. The fund provides grants of up to £500 to families with limited savings, a mechanism that ensures the limited resources available go to those in greatest need.

While all applications are considered, the grants typically go towards the travel costs of people visiting loved ones in hospital or rehabilitation, paying for emergency accommodation, providing breaks for carers, and meeting any additional costs incurred in the immediate aftermath of a brain injury.

You can find more details and apply online at www.headway.org.uk/supporting-you/headway-emergency-fund.

Section two:

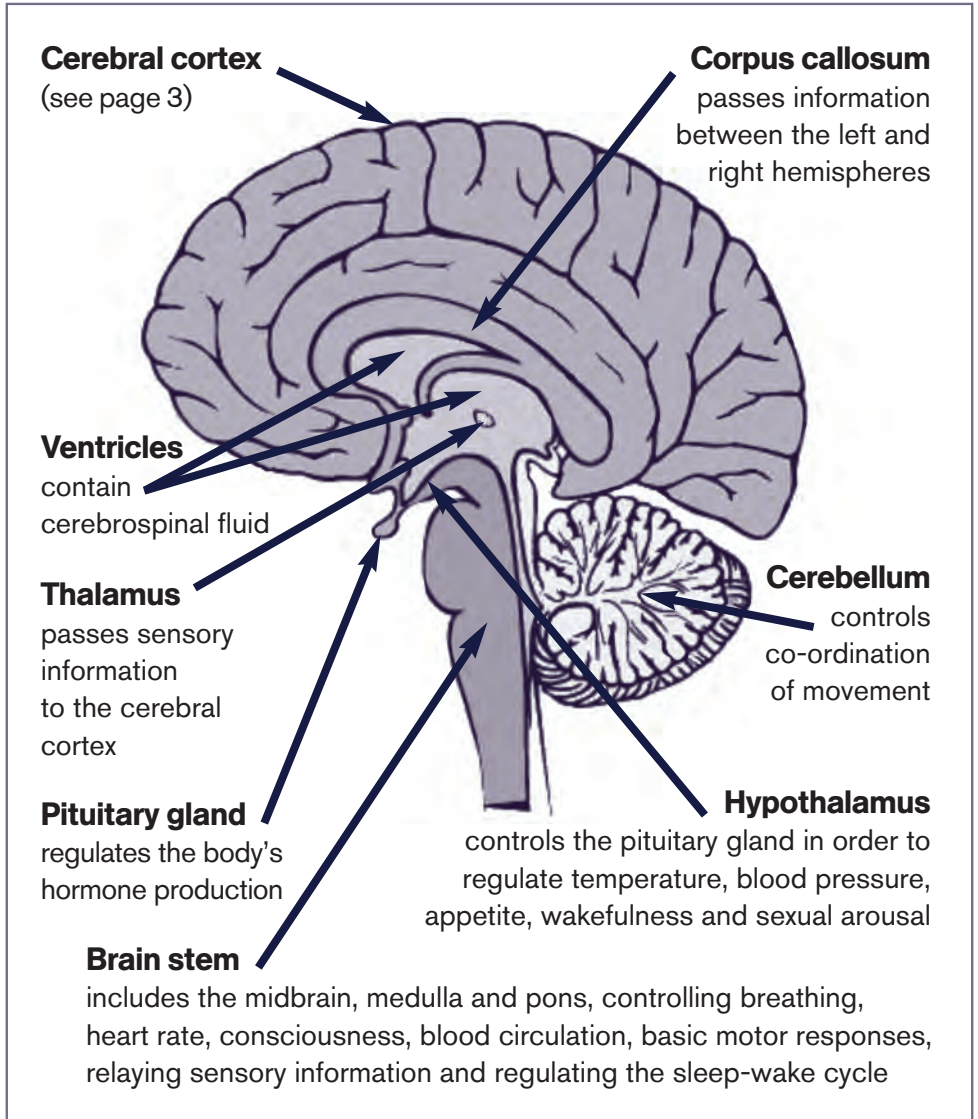
Understanding brain injury

Types of acquired brain injury

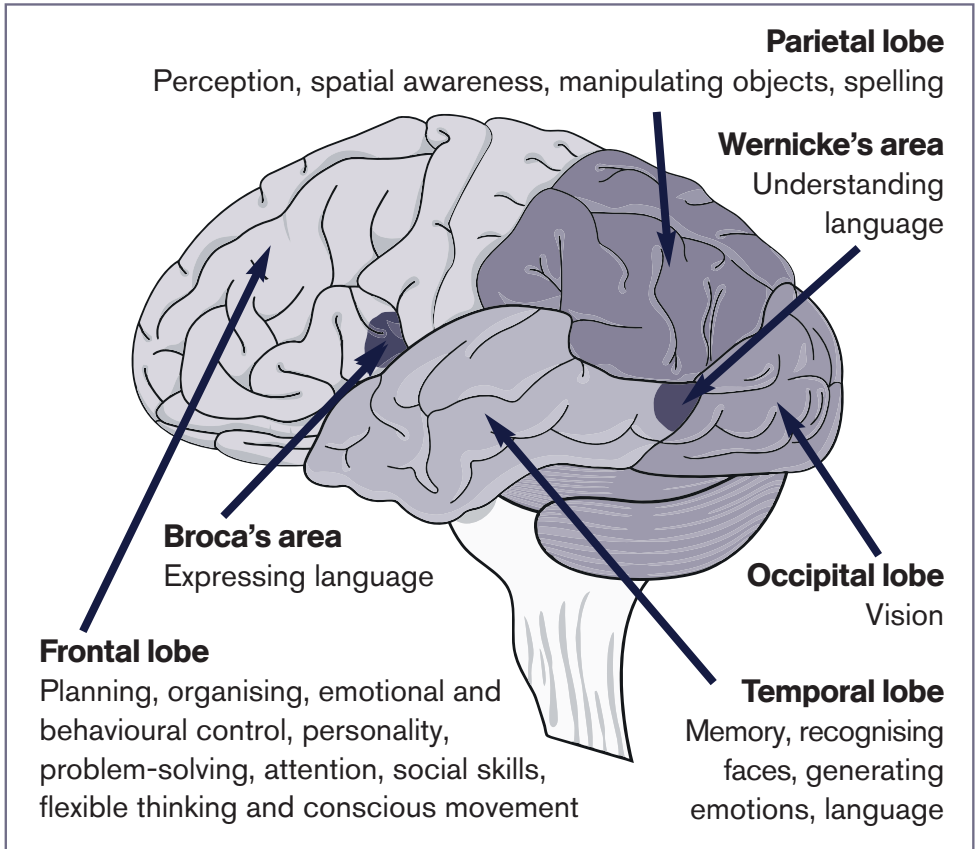
Brain injury takes many forms and has many causes and levels of severity. Any brain injury that has occurred since birth is known as an acquired brain injury (ABI). Common forms of ABI include:

- **Traumatic brain injury (TBI)** – commonly occurs due to road traffic collisions, falls, assaults, etc. TBIs are generally categorised into minor, moderate and severe injuries.
- **Stroke** – occurs when either the blood supply in the brain is blocked by a blood clot (ischaemic stroke) or when a blood vessel in the brain bursts (haemorrhagic stroke) causing a bleed on the brain (haemorrhage).
- **Encephalitis** – inflammation of the brain caused by either a viral infection or through the immune system attacking the brain in error.
- **Meningitis** – inflammation of the membranes that surround the brain (meninges) caused by bacterial or viral infections.
- **Hypoxic/anoxic injury** – caused by lack of oxygen to the brain and can happen as a result of a heart attack, near drowning, carbon monoxide poisoning, etc.
- **Brain tumour** – an abnormal growth of cells in the brain.
- **Hydrocephalus** – a build up of cerebrospinal fluid (CSF) in the brain. This often occurs in babies as a result of birth defects or infection and can also occur in adults due to traumatic brain injury, stroke, brain tumour, or, on rare occasions, spontaneously, with no known cause.

Internal areas of the brain and their functions



The cerebral cortex



The effects of brain injury

The brain is remarkably complex and controls everything we do, so brain injury can have a huge variety of effects, depending on the severity of the injury and the area of the brain that is affected. Due to this complexity, the level of recovery and the difficulties likely to be experienced can be impossible to predict in the early stages. The effects of your relative's brain injury may

only become fully apparent when they return home and have to start functioning in daily life again.

The possible effects of brain injury are many and varied and there isn't scope to cover them in detail in this booklet.

However, detailed information about many of the effects of brain injury are available in Headway's range of freely downloadable booklets and factsheets at

www.headway.org.uk/information-library.

For an overview of the common effects of brain injury, see the Headway booklet *The effects of brain injury and how to help*.

Early stages: Post-traumatic amnesia

After a period of unconsciousness, people often experience post-traumatic amnesia (PTA). People in PTA behave and talk in a bizarre, inappropriate manner. They have no continuous sense of the present and are unaware of where they are or what has happened. PTA can be very difficult for family members and medical staff to deal with and can last for a few hours up to a few weeks, but it is important to remember that PTA is a normal stage after a period of unconsciousness and it does pass in time. For further information, see the Headway factsheet *Post-traumatic amnesia* and the booklet *Hospital treatment and early recovery after brain injury*.

Long-term personality changes

Probably the most difficult effect of brain injury for families to come to terms with is a fundamental change in the nature and personality of a relative. It is in this respect that brain injury is unique among long-term physical disabilities. Many people report that it is very much like "living with a stranger" and "having to learn to love a completely different person". This

can be an even greater challenge when the survivor lacks insight into how their injury has affected them.

There are no easy answers to dealing with these issues. The people who cope best tend to be those who accept the changes in their relative and don't try to hang on to the person they were before the injury.

A carer's story

I found it very difficult to deal with Steven's behaviour. He shouted inappropriate things in public, not aware he was doing anything wrong. He was very angry and short tempered and was frustrated that he could not do the things he could before the accident. He also kept forgetting things, struggling with simple tasks and was becoming more and more depressed.


He had not received any rehabilitation after the accident, so, after contacting the Headway helpline to talk about the situation, I went to the GP and requested a referral to a neuropsychologist. The doctor was unsure at first and prescribed anti-depressants. These were not really effective, so I contacted some neuropsychologists in the area who I found listed in the British Psychological Society's directory. I found one who seemed really good so I returned to the doctor with the details and he gave us a referral.

The psychologist worked with Steven and I also attended some sessions, so we could work together on some issues. I was advised to put consistent boundaries in place, so every time inappropriate behaviour occurred I told him quietly that it was not acceptable. I am carrying on with this to try and raise his awareness and stop the outbursts. It has been a few months and he does seem to be coming to terms with the changes in himself a little more. I am also beginning to accept these changes and it really helps to attend a Headway carers' support group to talk to other carers about this.

Jean

Section three:

Leaving hospital



Once your relative is medically stable and any physical injuries have been treated, they may be ready to be discharged from the hospital. There are a number of options for where they go from there and it is very important that the right care pathway is agreed and arranged as early as possible.

In England, GP-led Clinical Commissioning Groups (CCGs) are responsible for commissioning secondary healthcare services, while social services are funded by local authorities. NHS Health Boards in Scotland and Local Health Boards (LHBs) in Wales are responsible for commissioning healthcare services in those countries, while local authorities fund social care. The Local Commissioning Groups (LCGs) in Northern Ireland fund health and social care services. On the Channel Islands, services are commissioned by the States of Jersey and States of Guernsey Health and Social Care Departments, while the Department of Health and Social Care for the Isle of Man is responsible for services there. For the purposes of this booklet, anyone funding healthcare services will be referred to as 'healthcare commissioners'.

The discharge process

Before discharge, your relative's health and social care needs should be assessed by one or more health professionals. There should then be a meeting in which their care pathway and its funding will be discussed. Social services staff should attend the meeting, together with hospital or rehabilitation

staff, close family members, and possibly the GP. A written discharge plan may be produced with a copy to go to the GP, while you can also request a copy.

It is important to make sure that the discharge process is done properly in order to ensure that the right care pathway is arranged and it may be useful to have an independent advocate to help you. Again, [PALS](#) or the equivalent support service in your area should be able to help you with this. [Headway groups and branches](#) can sometimes provide support at this stage, so if you need an advocate you could talk to the local group. [Citizens Advice](#) can also provide details of any local advocacy services. You can talk through these options and find other sources of local support by calling the [Headway helpline](#).

Assessment and funding for care

Your relative's care package will be assessed and funded in one of the following ways:

Continuing Healthcare

If your relative's main care needs are primarily health related, then they could be eligible for NHS Continuing Healthcare, which is a complete package of care funded by the NHS.

If it is decided that your relative may be eligible for NHS Continuing Healthcare then the healthcare commissioners should carry out a multi-disciplinary assessment of their needs. You will then need to discuss how their needs and care will be managed and the organisations that will be responsible for providing services.

Community Care

If your relative's needs do not meet the criteria for NHS Continuing Healthcare, they may be eligible for a joint package of care, which means the NHS and local authority will share responsibility for funding care services. Alternatively they may receive a community care package, funded solely by the local authority. More information on packages of care is available at www.nhs.uk/conditions/social-care-and-support.

In April 2015, the [Care Act 2014](#) came into force, providing new legislation for adult community care in England. According to the Act, local authorities must carry out a needs assessment for adults who need care, based only on whether it appears that the adult may have needs for care or support. Similar rules apply in the rest of the UK. Previously, local authorities would have their own way of assessing an adult's eligibility for services, based on national regulations. However, there is now a national eligibility threshold for adults who need care. This means that the level of services offered by each local authority should not be significantly different.

It is important that the person carrying out the assessment has knowledge, or is made aware, of the effects of the brain injury on your relative, particularly those which are of a hidden or

A carer's story

We had to return to the hospital for my husband's follow up appointment. Both of us struggled to communicate with the consultant and came out feeling quite confused.

*Before the next appointment we kept a diary of things that had happened and made a list of questions. While he couldn't answer all the questions, we did manage to explain the issues much more effectively and we both felt much better after the appointment. **Sonia***

subtle nature. You may find it useful to note down your relative's difficulties or keep a diary so that you are able to communicate them during the assessment.

If your relative meets the eligibility criteria, the local authority has a duty to provide services to meet those needs. A care and support plan will need to set out what kind of care will be provided. The local authority must also promote an individual's wellbeing and consider what services should be provided to prevent their needs from getting more serious. The services can be managed by the social services department, but people will usually be given a personal budget which can be used to manage and pay for their own care.

Differences around the UK

The above information on Continuing Healthcare and community care applies to England, Wales and Northern Ireland. In Scotland, NHS Continuing Healthcare was replaced by Hospital Based Complex Clinical Care in 2015, which focuses on providing care for patients in a home environment. More information on this is available at www.careinfoscotland.scot.

Challenging a decision

If you disagree with a decision made during an assessment, make sure you obtain a copy of it and the reasons why the help cannot be offered. You are able to challenge the healthcare commissioners or local authority, in writing, using their complaints procedure.

You can find detailed information about the complaints processes across the UK, Channel Islands and Isle of Man in the Headway factsheet [Making a complaint about health and social care services](#).

Care pathways

Once your relative's needs have been identified, the healthcare commissioners and/or local authority should outline them in a care plan. A review should take place within three months of the care being set up and annually thereafter. If your relative's needs change during that time then it is important to request a review. Your relative should receive one or more of the following options:

- Inpatient rehabilitation
- Outpatient rehabilitation
- Community rehabilitation
- Residential/nursing care
- Intermediate care
- Community care services

Rehabilitation after brain injury

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 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.

A carer's story

I was unsure about rehabilitation settings for my son. He had problems where he lived before the injury and so I really wanted an inpatient placement further away. One person within the commissioning group was saying that was a good idea, while another within the rehabilitation unit said it may be useful to be in familiar surroundings.

I was not sure what to do for the best. I visited the different units and talked to people who had already been through the programmes. I asked lots of questions, such as what will they be doing with my son? Could I have a copy of the care plan? What about daily schedules? What specialists work there and how many sessions would my son get with each? Would there be specialist cognitive rehabilitation and behavioural interventions and how could I be involved?

I also took into consideration staff, cleanliness, the general feel of the place and checked the CQC inspection reports. I made my decision and, although I could not be totally sure it would be right for him, it was the right decision at the time based on all the information I had.

David

Accessing rehabilitation services

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 the local authority, 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, availability of places and funding options 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:

Inpatient rehabilitation: This involves intensive specialist rehabilitation for people who are not yet ready to return home after discharge from hospital. Neurological rehabilitation centres, where a structured programme is in place at all times, provide an ideal setting for further treatment.

Outpatient rehabilitation: Some people 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.

Community rehabilitation: Following an inpatient rehabilitation stay, some people may be transferred to a residential transitional living unit. Here people can develop their independent living skills so that they may be able to live in a place of their own. Others will go straight back to their homes, with a community rehabilitation team or outreach team helping them to make further progress;

this may involve therapists working with the person in their home or community environment.

The role of family members in rehabilitation

The British Society of Rehabilitation Medicine (BSRM) has produced guidelines on rehabilitation after acquired brain injury, downloadable at www.bsrn.org.uk/publications/publications. The guidelines recognise the important role family members and carers play in the rehabilitation process:

“Family members are very often a crucial asset to the patient, providing both long-term support and a major contribution to the rehabilitation process. It is also important for the team to recognise that family members often have a special rapport with the patient and may detect subtle communication in advance of the professionals.

“Families can provide valuable insights into the patient’s character, choices and ambitions, as well as important information on the presentation of difficulties in the home setting. This is essential in initial assessment, and in the monitoring of rehabilitation gain, to minimise under-reporting of difficulties when the brain-injured person lacks insight” (Rehabilitation following acquired brain injury: national clinical guidelines, BSRM, 2003).

What if my relative is on a waiting list for rehabilitation?

Rehabilitation services can sometimes have long waiting lists and it might be weeks or even months before the brain injury survivor is able to receive rehabilitation. For many survivors and family members, this can be a difficult and confusing time. Information and tips for coping with this stage are available in

the Headway factsheet *Waiting for rehabilitation after brain injury*.

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 on **0808 800 2244**.

It is advisable to contact several units and visit them to assess their suitability before making a decision. There are several other directories of rehabilitation professionals in private practice and you can find details in the '[Useful organisations](#)' section.

For more detailed information on brain injury rehabilitation see the Headway booklet *Rehabilitation after brain injury* (see 'Further reading').

Residential/nursing care

If your relative no longer requires intensive rehabilitation, but isn't able to return home, they may be assessed as requiring long-term residential care. Funding will be means-tested, so your relative may have to contribute some of the costs themselves. However, if they are entitled to nursing care then this should be funded by NHS Continuing Healthcare.

There are many residential homes which specialise in caring for people with brain injuries. These units provide long-term rehabilitation services and enable people with brain injuries to continue to maximise their potential for improvement, so it is important to access one of these units if possible. You can check Care Quality Commission reports on services at www.cqc.org.uk.

There are a number of search and comparison websites for residential units and other care services. Some sites are listed under 'Information on care homes and care services' in the 'Useful organisations' section of this booklet.

Headway approved care providers

Headway has developed the Approved Provider accreditation scheme for NHS and independent care settings. The approved units specialise in acquired brain injury care and include hospitals, neuro-rehabilitation units, residential units, nursing homes and respite facilities.

- See www.headway.org.uk/supporting-you/in-your-area/approved-care-providers/ for details.

Intermediate care

If your relative does not require long-term care they may be provided with NHS funded Intermediate Care. This is an integrated programme of therapy and treatment, which can be provided for a few days, up to several weeks. It can take place in your relative's own home or in a care home and is designed to support the transition from hospital back into the home environment.

Community care services

It is important that you do not feel rushed into bringing your relative home before you are ready. Try not to feel under pressure from your relative (who may be very keen to get back to familiar surroundings), other family members, friends, or staff at the hospital, rehabilitation unit or care home. Only accept a proposed discharge date when you are certain that you and your relative have had the necessary community care assessments and that you have sufficient support and all necessary equipment in place at home.

If it is decided that your relative will return home, it may be a good idea to ask for a staged discharge, or 'trial run', first. This could involve them coming home once or twice a week, with an overnight stay, or whatever is best for you.

This will help you to find out if any adaptations will be needed for the home, such as wheelchair ramps and handrails, and will give you the opportunity to ask questions and get help while you are still in contact with the hospital or rehabilitation team.

An occupational therapist from the hospital, rehabilitation team or social services should visit the home initially to assess you and your relative's needs and any home adaptations that may be required.

Your relative is entitled to a needs assessment at any time, so even if they have been at home for a while they should seek an assessment. Local authorities throughout the UK have an obligation to carry out an assessment and make provisions for identified requirements. The Care Act (2014) sets out that adults in England should have their own wishes and

preferences taken into account when deciding on the services they receive.

Your relative may be entitled to the following community care services:

- Help with bathing and washing
- Help with getting up and going to bed
- Help with shopping
- Help with managing finances
- Help with cleaning, cooking and tidying the house
- Adaptations to the home
- Provision of meals by home delivery or at a day centre or lunch club
- Provision of recreational, educational and occupational activities, such as lectures, games and outings
- Help with transport and costs of transport
- Respite care to provide you with a break from caring

If your relative is assessed as requiring community care services then you will need to discuss arrangements for funding with the local authority. Your relative should be able to receive a personal budget so they can manage their own services (or you can do so on their behalf). The local authority can charge for services if people have assets above financial thresholds.

Adaptations to the home

If the local authority considers that adaptations to the home are necessary to meet your relative's needs, and that the work is reasonable and practical, then a means-tested Disabled Facilities Grant should be available to help to meet the costs. This is available in all parts of the UK except Scotland, so

Scottish residents should consult their local authority for information on any grants that are available.

An occupational therapist can assess the home and recommend the adaptations that will be needed. Adaptations that may be available include:

- Widening doors and installing ramps
- Providing or improving access to rooms and facilities – for example, by installing a stairlift or providing a downstairs bathroom
- Improving or providing a suitable heating system
- Adapting heating or lighting controls to make them easier to use
- Improving access and movement around the home.

There are also a number of organisations who supply equipment, guidance on purchasing the right supplies for your needs and grants to help with the cost. See '[Useful organisations](#)' or call the [Headway helpline](#) for further sources of information.

Purchasing care

If there has been no provision of social care you can purchase social care services, including home (domiciliary) care, from independent providers.

It is important to remember to try, wherever possible, to utilise services with some knowledge and experience of working with clients who have had a brain injury.

You can purchase care services via the following resources:

- The Care Quality Commission (CQC) has a search directory of care providers in England and inspection reports for each service at www.cqc.org.uk.
- A comprehensive list of homecare providers, committed to the United Kingdom Homecare Association (UKHCA) Code of Practice, is available from www.ukhca.co.uk or by telephoning **020 8661 8188**.
- You will find homecare providers listed in Yellow Pages under 'Nurses' Agencies and Care Agencies' or 'Homecare Services'. You will also find details on the Yellow Pages website at www.yell.com. In the Thomson Directory, providers are listed under 'Homecare Services' or 'Home Help Services – Private'. Look out for the UKHCA logo in adverts in both directories.
- Social services departments may be able to provide a list of their approved organisations in your area.
- You can look for services and manage a budget for direct payments at www.shop4support.com.
- The Community Care website at www.communitycare.co.uk is a good source of information on social care services.

Section four: Becoming a carer

When your relative comes home there may be many new challenges to face. This section of the booklet outlines your rights and entitlements as a carer and some key practical issues you might need to think about.

Carers' assessments

A carers' assessment looks at your needs as a carer and whether you are entitled to services to make caring easier for you. You can contact your local authority to request an assessment (for contact details visit www.gov.uk/find-your-local-council).

According to The Care Act 2014, any carer in England who needs support or who may need support in the future based on the appearance of needs is entitled to an assessment. The emphasis on appearance of needs differs from previous legislation, as it means that you do not have to ask the local authority for an assessment, and you do not need to substantiate the amount of care that you are providing.

However, it is always best practice to ask for an assessment and to do this in writing. These rules apply to adult carers only (18 and over) and young carers who are approaching adulthood. For carers under 18, the Children and Families Act 2014 outlines the law for young carers.

In Wales, the Social Services and Well-being Act 2014 gives carers the right to have an assessment based on the appearance of needs. The Act also incorporates the need to

conduct a holistic assessment accounting for the carers' outside interests and wishes in day-to-day life to promote wellbeing.

Legislation in Scotland and Northern Ireland retains the requirement to provide a 'regular and significant/substantial amount of care'. However, this is not clearly defined and you are advised to request an assessment no matter how much care you provide. Legislation in the Isle of Man and Channel Islands is less clear but social services do provide assessments so it is suggested that you request one.

You can also ask for an assessment if you *intend* to provide care so it is a good idea to have the assessment while your relative is still in hospital so you have services in place when they come home.

Carer's assessment checklist

There are a number of issues you might want to think about raising in the assessment and the following checklist might help (describe everything to the social worker in as much detail as you can):

Housing

- Do you and the person you care for live together or apart? Is this arrangement satisfactory? If not, what changes are needed?
- Does the person you care for have difficulty moving about in the home? For example, can they climb the stairs or bathe on their own?
- Would aids or adaptations to your home make it easier for you and the person you look after?

Health

- Does the person you care for have any health (including cognitive, behavioural, emotional and physical) problems you find hard to deal with?
- Are you getting enough sleep?
- Do you have any health problems? Are you stressed, anxious or depressed?

Work

- Are you struggling to combine work and caring?
- Have you had to reduce your hours of work?
- Would you like to return to work?

Other interests

- Do you want to do any training or adult education?
- Do you want to pursue any leisure interests but can't because of your caring role?

Time

- How many hours a week do you provide care? Include all the time you spend with the person you care for, the tasks you do for them and how long they take you.
- Do you have to help with – housework.. shopping.. extra laundry.. bathing.. toileting.. cooking.. other personal care.. ensuring they don't come to any harm.. dealing with money/pensions.. administering medications.. keeping them company.. going to the shops with them.. taking them to hospital?
- Do you have to help during the day or night – or both?
- Does anyone else help? Who and for how long? Would they like some help with these jobs?
- List the tasks you would most like help with, putting the most important first.

Feelings

- Do you feel you don't have a choice about providing care? You may feel that you can't cope at all, or only if you reduce the amount that you do.
- What would you most like to change about your situation?

Relationships

- Is caring affecting your relationship with the person you look after, other family members and friends?
- If you are a parent, is caring making this role harder? Do you feel you have time for your children?

Dealing with emergencies and unplanned events

- Do you need help in planning what happens if you suddenly become ill or have an emergency?
- Do you know who to contact in an emergency?

The future

- Are you concerned about the future for you and the person you care for?
- If you are a young carer, make sure you ask for the impact on your education, social life, etc, to be taken into account.

There may be other issues to consider. Please visit the Carers UK website at www.carersuk.org and search 'carer's assessment' for up-to-date information.

Social care support for carers

After an assessment, social services will develop a care plan aimed at improving your wellbeing, which should include the support and services that you have been assessed as needing. You should receive a personal budget to pay for the services.

You may be entitled to the following support from social services:

- Help with housework and looking after your relative
- Equipment and adaptations to the home
- Emotional support
- Breaks from caring

Some services may be means-tested, so after the assessment your local council will look at your income and capital (savings and property) to decide which care services, if any, you will be charged for. There is no blanket policy on charging for services, so this will vary among local authorities. Your initial right to an assessment is not linked to your income or capital.

Carers emergency schemes

It is very important to know that the person you care for is looked after should anything happen to you unexpectedly. Many areas run carers emergency schemes which can provide a support network if you are suddenly unable to provide care.

In some areas of England there are two levels of emergency care. In level one you provide the names of two friends, neighbours or relatives who can check on the person you care for. Level two is appropriate if the person requires a lot of care. This gives you a professional support worker who can take over from you for a while.

The availability and nature of the scheme varies throughout the UK. You should discuss registering with your local scheme during your carer's assessment. You can also contact your local social services at any time and NHS Carers Direct can provide contact details for schemes in England.

If there is no scheme in your area then you could make a card of your own with details of who to contact in an emergency. It is important to remember not to put information about the person you care for or their address in case the card falls into the wrong hands.

For information about creating an emergency plan, visit www.carersuk.org/search/planning-for-emergencies.

Making a complaint about social services and care homes

You may wish to raise concerns about how assessments for yourself or your relative were carried out, challenge decisions about what care will be provided, challenge the amount that is being charged for services, or complain about the treatment being provided. If your complaint is on behalf of the person you care for, you must have their consent if they have the capacity to do so.

- You should first contact the local authority or care home responsible and go through their internal complaints procedure.
- If you are still not satisfied, you can complain to the Local Government and Social Care Ombudsman (LGO), which can investigate individual complaints in England. Details can be found on their website at www.lgo.org.uk and you can contact the LGO for information and advice on **0300 061 0614**. There are equivalent Ombudsman services and care

service regulators in Scotland, Wales and Northern Ireland. You can find contact details in the 'Useful organisations' section. For more detailed information see the Headway factsheet *Making a complaint about health and social care services*.

Benefits and entitlements

There are a range of benefits and other forms of financial support that you may be entitled to. Many of these are available if the person you care for is receiving Disability Living Allowance (DLA), or its replacement Personal Independence Payment (PIP). Here is a brief overview:

- **Carer's Allowance (CA)** – This benefit can be claimed if you are 16 years-old or over and the person you are caring for is getting the middle or highest care rate of DLA, PIP, Attendance Allowance or Constant Attendance Allowance. You must be providing care for at least 35 hours per week, earn £110 a week or less and not be in full-time education. Entitlement to CA can lead to an increase in some other benefits, through the inclusion of the Carer's Premium. Note that if someone else looks after the same person, only one of you can get CA.
- **National Insurance Contribution Credits** – If you do not earn enough to pay National Insurance, entitlement to Carer's Allowance allows you to build National Insurance credits towards other benefits and a retirement pension.
- **Grants** – Some assistance may be available in the form of a grant. Grants that may be available in other areas include budgeting loans, local council grants, the Scottish Welfare Fund and the Discretionary Assistance Fund (for Welsh residents) and Community Care Grants.

- **Carer's Credit** – This is available to people who provide care for one or more disabled person(s) for 20 hours or more per week, where they do not currently receive Carer's Allowance. This will build up your National Insurance contributions towards other benefits and a retirement pension.

Vehicles and transport

- **The Motability Scheme** – This scheme helps people on the Higher Rate Mobility Component of DLA or PIP to buy or lease a car at an affordable price. If you care for a disabled person who doesn't drive, they can still access the scheme with a nominated person as their driver. The Motability Scheme also makes scooters and powered wheelchairs available. More information is available from Motability at www.motability.co.uk or by calling **0300 456 4566**.
- **The Blue Badge parking scheme** – This scheme allows wider access to parking for disabled people. If you are caring for a disabled person who doesn't drive, they can nominate you as their driver so that you can use their Blue Badge for purposes directly benefiting them.
- **Disabled Person's Railcard** – If you are caring for someone who has a Disabled Person's Railcard, you can receive the same discount as them when travelling with them.
- There are schemes available to help with transport to your relative's outpatient appointments. Hospitals and rehabilitation centres provide transport for patients and this will often extend to carers as well. If your relative is entitled to certain benefits they will be eligible for the **Healthcare/Hospital Travel Costs Scheme**, and will also be able to reclaim your travel costs if you have to go with them to an appointment for medical reasons.

Many local councils have their own schemes, so check with yours for details. For example, Discretionary Care Grants may be available for the costs of hospital visits if you are in receipt of certain benefits.

Leisure

- **Cinema Exhibitors' Association Card** – This is a national card for people who receive disability benefits, which entitles the holder to one free ticket for a person accompanying them to a participating cinema.
- Many museums, galleries, theatres, etc, offer discounts for disabled people and their carers. Remember to ring ahead to ask.
- The book *Rough Guide to Accessible Britain* provides information on holiday destinations for disabled people. It is freely downloadable from www.accessibleguide.co.uk.
- The Headway factsheet *Holidays and travel after brain injury* provides information on holiday providers and travel insurance companies for people with a brain injury.

Benefits and entitlements change over time. For the latest information, please visit www.gov.uk.

Applying for benefits for your relative

Your relative may be entitled to claim benefits and you may need to help them or even complete the forms on their behalf. The process of claiming disability benefits after brain injury can be complex, because the subtle or hidden symptoms can be difficult to convey on the claim forms.

- It is important to seek support from someone experienced in claiming benefits after brain injury and many of [Headway's Groups and Branches](#) can help.

- The [Headway helpline](#) can signpost to specialist sources of support.
- There are organisations that specialise in offering information on benefits, such as Turn2Us at www.turn2us.org.uk. They also have a benefits calculator that can advise on what benefits your relative could be entitled to based upon their circumstance.
- The Citizens Advice and the local authority's welfare rights officer are also good sources of support, but they may not have specific experience with brain injury.
- The Headway website is regularly updated with information on the current changes to the benefits system. Visit www.headway.org.uk for news and guidance.
- Headway's booklet *A guide to welfare benefits after brain injury* also contains helpful information about welfare benefits.
- Keep copies of medical records, letters from the GP or hospital, and your own notes, as these can be valuable accompanying evidence for claims.

For further sources of support and information see '[Useful organisations](#)'.

Employment

The following pieces of legislation protect the rights of carers at work:

- **The Equality Act (2010)** protects you from direct discrimination and harassment at work due to your caring duties. This includes employers refusing to offer you a job or treating you less favourably because of your caring responsibilities. It also covers unfair expectations, offensive language and intimidating behaviour.

- **The Employment Act (2002)** gives carers a legal right to ask your employer for flexible working hours. However, there is no legal obligation for the employer to grant this request, although they must give a valid business reason for refusing. You also have the right to take unpaid time off work to look after someone in an emergency.

Combining work or study with caring is very difficult, but for financial reasons, and in order to maintain a life away from caring, you should only give them up if you really have to. If you are concerned that you aren't being treated fairly at work due to your caring responsibilities the [ACAS](#) helpline can offer free, confidential advice on **0300 123 1100**.

Administering medication

Your relative may have been prescribed medication, possibly several different kinds, which you may be responsible for administering.

This is extremely important and the following should be noted:

- You should mention this issue at the discharge meeting and during a carer's assessment.
- Make sure you are confident about what you have to do, and any potential side-effects of the medication, before your relative is discharged home.
- Make sure you get very clear instructions about dosages and the times to administer them.
- If your relative has returned home and you both still have questions about their medication, you should start by talking to the GP and/or pharmacist as soon as possible.

- Try to arrange professional support if possible. You may be able to arrange home visits from the district nurse to help.

If your relative will be responsible for administering their own medication then there are a number of products available which can help, especially for people with memory problems. You can purchase pill boxes which only dispense the correct dose at the correct time and there are a wide variety of reminder systems which provide cues for taking medication and other daily activities. For more information, see the Headway factsheet *Coping with memory problems –practical strategies*.

Making decisions on your relative's behalf

You or the professionals in charge of your relative's care may consider that they don't have the capacity to make their own decisions in certain areas of their life. If this is the case then it is possible to apply to the Court of Protection for you, a family member, friend or professional to be appointed as a Deputy and make decisions on their behalf under the Mental Capacity Act (2005). Decisions made on someone's behalf are situation specific and must be judged to be in the person's best interests.

The issues surrounding this are complex and further information can be found in the Headway booklet *Mental capacity: supporting decision making after brain injury* and by contacting the [Headway helpline](#).

A carer's story

My husband always dealt with the financial side of things, banks, bills, etc, but after the injury he lost the capacity to make any decisions. We had not assigned a lasting power of attorney before the accident, so I had to apply to be a deputy through the court of protection.

I applied to take over financial and welfare decisions. I seriously considered involving a solicitor to act as a deputy, allowing them to take over paperwork and take away some of the stress. However, I felt I wanted to take on this responsibility, even though I knew it was a big one. It took 6-8 weeks for the papers to come through and, in the meantime, I had to inform the bank and the mortgage company what was happening and put everything in writing.

Now I can make the decisions that I know he would have made himself and that are in his best interests. I can also call upon the solicitors for advice and have to consult the Court of Protection for any major decisions.

Julie

Section five: Relationships

Adjusting to family role changes

Brain injury can radically alter the dynamics of families and relationships, especially if the person with the brain injury was previously the main wage earner and can no longer work. Roles and responsibilities within the family can change and this can be very hard to get used to at first.

These changes can cause problems and there can often be a lot of resentment and tension. However, there can also be a lot of positive changes and a strengthening of relationships. For example, your relative might now get the chance to spend more time with their children and the bond between them could strengthen as a result.

It is important to try to be aware of the reactions of different family members and to keep everyone included in order to prevent feelings of isolation. If any family members seem to be having particular trouble adjusting then try to let them know that their feelings are normal and natural.

It is also important to work with your relative's therapists on family and relationship issues. The therapists should consider the family as a whole as part of the rehabilitation process.

For more information and tips for managing different types of relationships after brain injury, see Headway's [relationships booklets and factsheets](#).

Changes to sexual relationships

Sexual difficulties can be embarrassing to talk about, but are particularly important to deal with. It helps for both partners to

■ Caring for someone with a brain injury

talk things through with a qualified counsellor, preferably one with knowledge and experience of brain injury. A clinical neuropsychologist who specialises in sexual relationships would be ideal, but specialist relationship and sex counselling is also available from the organisation [Relate](#) (see 'Useful organisations'). You can also find accredited sexual and relationship therapists from the College of Sexual and Relationship Therapists at www.cosrt.org.uk.

Further information about changes to sexual relationships is available in the Headway booklet *Sex and sexuality after brain injury*. Headway also runs a training course called *Sex and sexuality after brain injury* which provides a useful introduction to the subject. Further details of the course and how to book a place can found on the 'Professionals' section of the Headway website.

Friends

Your relative's friends can be just as affected by the injury and its consequences as the family, but won't have the same support and may struggle to manage their feelings. It is easy for friends to drift away and lose touch, often not because they want to, but because they don't know how to deal with the situation or don't want to get in the way.

Try to keep in touch with both your relative's friends and your own. Keep them involved by giving them certain jobs to do, which could also take some of the pressure off you. Friends will often be more than happy to take over some caring duties for a while, which can prevent your relative from becoming socially isolated and give you a break.

It is also a good idea to pass on any literature which you have found helpful, or instance Headway's factsheet *Brain injury: a guide for friends*.

Section six:

Caring for yourself

Maintaining interests and social life

It can be very difficult to combine an active social life with the demands of being a carer. This can mean that you lose contact with old friends and, when that happens, it can be difficult to re-establish friendships.

It is important to remember that maintaining friendships is a vital part of a healthy and happy life. Friends can be an important source of emotional support as well as providing an opportunity to get away from the demands of home life for a while, all of which can help you to look after yourself and your relative more effectively.

It is also important to maintain your hobbies and interests, both those that involve social interaction and also solitary pursuits such as music, reading, watching films, etc. This may seem obvious, but it is easy to let the demands of caring dominate your life. Making time for activities that make you happy can make all the difference to your quality of life.

Staying healthy

Being a carer is very stressful and time consuming and it can be easy to let yourself stop making the effort to eat healthily and engage in exercise. This is self-defeating, because being fit and healthy helps you to deal with stress and cope better with everyday life.

Also, research shows that people who have high levels of stress are more prone to illness and slower to recover than less stressed people. Stress can even make cuts and other wounds heal more slowly.

Maintaining a healthy lifestyle can counter these negative effects of stress and improve your sense of wellbeing and quality of life. Try to take time to do whatever forms of exercise you enjoy and make the effort to eat a healthy, balanced diet. It is also important to remember to see your GP with any health concerns.

You can find information on exercise and healthy eating on the NHS website at www.nhs.uk/livewell.

Taking a break from caring

It is important to take a break from caring on occasion in order to rest and have some time to yourself. Provision and funding for respite care should be made in your relative's care package and the services provided by your own carer's assessment.

There are a number of options available for respite care:

- Many residential and nursing care homes can provide short-term care for your relative.
- Headway groups and other day services can provide respite care for a few hours a week.
- There are many providers of holidays for disabled people, which provide a break for both your relative and yourself.
- It is often possible to arrange home support for your relative in order to go away on holiday yourself.

Some social services departments operate voucher schemes to provide respite carers. You can also use direct payments to pay for respite care. Contact your local authority to find out the help that they can provide. Carers' organisations and the [Headway helpline](#) can also provide details of respite and holiday providers (see 'Useful organisations').

Carer support groups

Often the best source of support is other carers in a similar situation to yourself. Many of Headway's groups and branches provide support group meetings and one-to-one support for carers. These services are particularly helpful as they provide peer support from others in similar situations.

You can find details of your nearest Headway group or branch at www.headway.org.uk/supporting-you.

Specialist carers' organisations, such as [Carers UK](#), offer support groups and services in many areas of the UK. Your local council should be able to signpost to other local groups. The NHS Carers Direct helpline can also provide information about groups and services in England.

Contact details for these services are available in the 'Useful organisations' section.

Section seven:

Young carers

Following your relative's brain injury young people in the family may take on practical and/or emotional caring responsibilities that they may not have undertaken before, such as looking after your relative or other siblings.


Being a young carer can affect many areas of a young person's life including school, college, work and university. If you are a young carer, or you are concerned about a young person within the family who has taken on a caring role, the following sources of support are available:

- **Carers Trust** will be able to tell you about any young carer projects in your area. They also have a number of young carer services across the country.
- **Carers Direct** has advice and information about being a young carer and can refer you to sources of support and further help. You can call them on **0300 123 1053**. Alternatively, you can visit the young carers pages of the website at www.nhs.uk/carersdirect/young.
- **Childline** – If you are a young person and would like to talk to someone in confidence Childline provides a confidential listening service. Calls are free to **0800 1111** or visit www.childline.org.uk for more information.
- **The Children's Society** has a number of projects to support young carers, families and professionals. Visit www.childrenssociety.org.uk/youngcarer for more information.

- **Barnados** runs projects across the UK which support young carers and their families in a variety of ways. Visit www.barnados.org.uk for more information.
- **Crossroads Young Carers Project** provides support for young carers in Northern Ireland. Visit www.crossroadsyoungcarers.co.uk for more information.
- Some of Headway's groups and branches also run support groups and services specifically for young carers. Contact your local group or branch to find out if they have services you can access. You can find contact details at www.headway.org.uk/supporting-you/in-your-area or by calling the helpline on **0808 800 2244**.

The Children and Families Act 2014 sets out new rules for young carers, defined as those under the age of 18. Under the new provisions, local authorities must provide carer's assessments for young carers who may have support needs, even if the carer hasn't requested an assessment. The Act also puts greater responsibility on local authorities to provide any support the carer requires.


Section eight: Ageing carers

 Carers of a brain injury survivor typically have a number of practical things to regularly think about, such as managing finances, making appointments, preparing meals and providing transport. Many carers are conscious of how key their role is in the survivor's life, and can be troubled by the thought of who will care for the survivor when they are no longer able to themselves due to age, or when they are gone.

This is something that none of us like to think about, but is unavoidable for carers who have been the primary, and often only, form of support available to a survivor.

Headway's factsheet [Ageing carers](#) offers information about this and practical suggestions of how to make future arrangements.

Section nine: Conclusion



Becoming a carer is one of the most difficult challenges anyone can face. Caring for a relative who has experienced a brain injury can be particularly daunting, due to the effects on their personality and cognitive functions, as well as any physical disabilities.

When a relative survives a brain injury, life can change completely without any warning and the resulting problems can be overwhelming. However, there can be both positive and negative aspects to the changes.

There are many things that you can do to help both your relative and yourself. Hopefully this booklet has helped you to identify your particular areas of need and access sources of support to address them.

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 freely downloadable booklets and factsheets covering the issues that brain injury can cause. The following examples provide further detail on subjects mentioned in this booklet:

Booklets:

- *A guide to welfare benefits after brain injury*
- *Claiming compensation after brain injury*
- *Claiming compensation in Scotland after brain injury*
- *The effects of brain injury and how to help*
- *Hospital treatment and early recovery after brain injury*
- *Mental capacity: supporting decision making after brain injury*
- *Parenting after brain injury*
- *Redeveloping skills after brain injury*
- *Rehabilitation after brain injury*
- *Relationships after brain injury*
- *Sex and sexuality after brain injury*

Factsheets:

- *About the brain*
- *Ageing carers*
- *Brain injury: a guide for friends*
- *Brain injury: a guide for grandparents*
- *Brain injury: a guide for parents*
- *Brain injury: a guide for partners*
- *Brain injury: a guide for siblings*
- *Coma and reduced awareness states*
- *Lack of insight after brain injury*
- *Making a complaint about health and social care services*
- *Managing anger – Tips for families, friends and carers*
- *Post-traumatic amnesia*
- *The effects of brain injury*
- *Waiting for rehabilitation after brain injury*


■ Caring for someone with a brain injury

To obtain a complete publications list or to order copies of books and booklets, please visit our website at www.headway.org.uk, or telephone **0115 924 0800**.

Factsheets and e-booklets are free to download from the website.

Brain injury survivors and carers can receive free copies of appropriate print booklets by contacting Headway helpline on 0808 800 2244 or by email at helpline@headway.org.uk.

Guidelines on pathways, services and treatments



Head injury: assessment and early management, NICE (National Institute for Health and Clinical Excellence), 2017

This guideline focuses on the early stages of treatment and includes guidance on what to do if someone has a head injury and what should happen in any admission to hospital and after discharge home. Available at www.nice.org.uk/guidance/CG176.

Rehabilitation following acquired brain injury – national clinical guidelines, British Society of Rehabilitation Medicine and the Royal College of Physicians, 2003

This provides guidelines and sets standards of care so that rehabilitation after brain injury can enable people to achieve the highest possible quality of life. Available at www.bsrm.org.uk/publications.

Early management of patients with a head injury, SIGN (Scottish Intercollegiate Guidance Network), 2009

This guideline makes recommendations on the early management of adults and children with head injury. Available at www.sign.ac.uk.

Vocational assessment and rehabilitation after acquired brain injury: inter-agency guidelines, Royal College of Physicians, British Society of Rehabilitation Medicine and Department for Work and Pensions, 2004

■ Caring for someone with a brain injury

This guideline outlines the rehabilitation services that should be available in order to maximise the potential for returning to employment after brain injury. Available from www.bsrm.org.uk.

Brain injury rehabilitation in adults: a national clinical guideline, SIGN (Scottish Intercollegiate Guidance Network), 2013

This guideline provides recommendations about post-acute assessment for adults over 16 years of age with brain injuries and outlines interventions for cognitive, communicative, emotional, behavioural and physical rehabilitation. Available at www.sign.ac.uk.

Useful organisations

Carers' organisations

Carers Federation

Tel: 0115 9629 310

Email: info@carersfederation.co.uk

Web: www.carersfederation.co.uk

Carers Trust

Tel: 0300 772 9600

Email: info@carers.org

Web: www.carers.org

Carers UK

CarersLine: 0808 808 7777

E-mail: advice@carersuk.org

Web: www.carersuk.org

Crossroads Caring for Carers (Northern Ireland)

Tel: 028 9181 4455

Email: info@crossroadscare.co.uk

Web: www.crossroadscare.co.uk

NHS Carers Direct

Helpline: 0300 123 1053

Web: www.nhs.uk/carersdirect

General advice and information

Advisory, Conciliation and Arbitration Service (ACAS)

Helpline: 0300 123 1100

Web: www.acas.org.uk

Citizens Advice

Web: www.citizensadvice.org.uk

Government services and information

Web: www.gov.uk

Disability Rights UK

Tel: 0330 995 0400

Email: enquiries@disabilityrightsuk.org

Web: www.disabilityrightsuk.org

Equality and Human Rights Commission Helpline

Equality Advisory and Support

Service: 0808 800 0082

Web: www.equalityhumanrights.com

Scottish Independent Advocacy Alliance (SIAA)

Tel: 0131 524 1975

Email: enquiry@siaa.org.uk

Web: www.siaa.org.uk

Health and social care services support

Board of Community Health Councils in Wales

Tel: 02920 235 558

Email: enquiries@waleschc.org.uk

Web: www.wales.nhs.uk/sitesplus/899/home

Care Inspectorate (Scotland)

Tel: 0345 600 9527

Email: enquiries@careinspectorate.com

Web: www.careinspectorate.com

Care Quality Commission (CQC) (England)

Tel: 03000 616161

Email: enquiries@cqc.org.uk

Web: www.cqc.org.uk

Care and Social Services

Inspectorate Wales (CSSIW)

Web: www.cssiw.org.uk

Health and Social Care in Northern Ireland

Web: www.hscni.net

Health in Wales

Web: www.wales.nhs.uk

Healthwatch England

Tel: 03000 683 000

Email: enquiries@healthwatch.co.uk

Web: www.healthwatch.co.uk

Local Government Ombudsman (LGO)

Tel: 0300 061 0614

Web: www.lgo.org.uk

NI Direct (Northern Ireland government and health information services)

Web: www.nidirect.gov.uk

NHS Scotland

Web: www.scot.nhs.uk

NHS Complaints Advocacy Service

Tel: 0300 330 5454

Email: nhscomplaints@voiceability.org

Web:

www.nhscomplaintsadvocacy.org

Northern Ireland Ombudsman

Tel: 02890 233821

Email: ombudsman@ni-ombudsman.org.uk

@ni-ombudsman.org.uk

Web: www.ni-ombudsman.org.uk

Parliamentary and Health Services Ombudsman (England)

Tel: 0345 015 4033

Web: www.ombudsman.org.uk

Patient Advice and Support Service (PASS) (Scotland)

Tel: 0800 917 2127

Web: www.cas.org.uk/pass

Patient and Client Council (Northern Ireland)

Tel: 0800 917 0222

Email: info.pcc@hscni.net

Web: www.patientclientcouncil.hscni.net

Public Services Ombudsman for Wales

Tel: 0300 790 0203

Web: www.ombudsman-wales.org.uk

The Regulation and Quality Improvement Authority (RQIA) (Northern Ireland)

Tel: 028 9051 7500

Email: info@rqia.org.uk

Web: www.rqia.org.uk

Scottish Public Services Ombudsman

Tel: 0800 377 7330

Web: www.spso.org.uk

Financial support

Attendance Allowance Helpline

Tel: 0800 731 0122

Carer's Allowance Unit

Tel: 0800 731 0297

Disability Information and Advice Line (DIAL)

Tel: 0808 800 3333
Web: www.scope.org.uk/dial

Tax Credits Helpline

Tel: 0345 300 3900

Turn2us

Provides guidance on accessing grants and benefits.

Helpline: 0808 802 2000
Web: www.turn2us.org.uk

Disability aids and equipment

There are several companies that supply specialist aids and equipment direct to the public through their catalogues.

An occupational therapist may also be able to help you obtain any items which you find difficult to locate.

DEMAND

Tel: 01923 681 800
Web: www.demand.org.uk

Disability Equipment Register

Tel: 07845 041 678
Web: www.disabilityequipmentservice.co.uk

Disabled Living Foundation (DLF)

Helpline: 0300 999 0004
Email: info@dlf.org.uk
Web: www.dlf.org.uk

Hearing and Mobility

Tel: 0800 0334 060
Email: enquiries@hearingandmobility.com
Web: www.hearingandmobility.co.uk

Motability

Tel: 0300 456 4566
Web: www.motability.co.uk

NRS Healthcare

Tel: 0345 121 8111
Email: customerservice@nrshealthcare.co.uk
Web: www.nrshealthcare.co.uk

Performance Health

Tel: 03448 730 035
Email: ukmedicalsales@performancehealth.com

Remap

Tel: 01732 760 209
Email: data@remap.org.uk
Web: www.remap.org.uk

Rica

Tel: 020 7427 2460
Email: mail@rica.org.uk
Web: www.rica.org.uk

Brain injury and other disability charities

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: 0161 707 6441
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

Tel: 0808 800 0004
Email: info@thebraintumourcharity.org
Web: www.thebraintumourcharity.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: info@cbituk.org
Web: www.childbraininjurytrust.org.uk

Different Strokes

Helpline: 01908 317 618
Email: info@differentstrokes.co.uk
Web: www.differentstrokes.co.uk

Encephalitis Society

Helpline: 01653 699 599
Email: mail@encephalitis.info
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
Email: fromthehelpline@epilepsysociety.org.uk
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

Outsiders (sex and disability helpline)

Helpline: 07770 884 985
Email: info@outsiders.org.uk
Web: www.outsiders.org.uk

Pituitary Foundation, The

Helpline: 0117 370 1320
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 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 Rehabilitation of Communication and Oral Skills (ARCOS)

Helpline: 01684 576 795
Email: admin@arcos.org.uk
Web: www.arcos.org.uk

BrainNav – The National Brain Injury Service Directory

Web: www.brainnav.info

Association of Speech and Language Therapists in Independent Practice

Tel: 0203 002 3704
Web: www.helpwithtalking.com

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 762 6440
Email: secretary@babicm.org
Web: www.babicm.org

British Psychological Society (BPS)

Tel: 0116 254 9568
Email: enquiries@bps.org.uk
Web: www.bps.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 325 2500
Web: www.counselling-directory.org.uk

Find a Therapist – UK & Ireland Directory of Counselling and Psychotherapy

Web: www.cpdirectory.com

Physio First

Tel: 01604 684 960
Email: minerva@physiofirst.org.uk
Web: www.physiofirst.org.uk

Relate – the relationship people

Tel: 0300 100 1234
Email: enquiries@relate.org.uk
Web: www.relate.org.uk

Royal College of Occupational Therapists

Tel: 020 7357 6480
Email: reception@rcot.co.uk
Web: www.rcot.co.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

Information on care homes and care services

Age UK

Helpline: 0800 055 6112
Email: contact@ageuk.org.uk
Web: www.ageuk.org.uk

Better Care Guide

Web: www.bettercareguide.org

Care Choices

Tel: 0800 389 2077
Web: www.carechoices.co.uk

Carehome.co.uk

Tel: 01488 684321
Web: www.carehome.co.uk

Care Information Scotland

Tel: 0800 011 3200
Web: www.careinfoscotland.scot

Care Quality Commission (CQC)

Tel: 03000 616161
Email: enquiries@cqc.org.uk
Web: www.cqc.org.uk

Community Care

Web: www.communitycare.co.uk

Compare All Care

Web: www.compare-all-care.co.uk

Good Care Guide

Email: support@goodcareguide.co.uk
Web: www.goodcareguide.co.uk

Local authority social services

*Contact your local council.
Details are available from the local telephone directory or online at www.gov.uk.*

Headway Approved Provider scheme

Web: www.headway.org.uk/supporting-you/in-your-area/approved-care-providers/

NHS Choices care search

Web: www.nhs.uk/Service-Search/Care-homes-and-care-at-home/LocationSearch/11

United Kingdom Homecare Association (UKHCA)

Helpline: 020 8661 8188
Email: enquiries@ukhca.co.uk
Web: www.ukhca.co.uk

Who's who in treatment and rehabilitation

The following professions are commonly involved in the assessment, diagnosis, treatment or rehabilitation of people with a brain injury.

- **Case manager:** responsible for overseeing and managing the overall care of people with a brain injury. They 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. They are not funded by the NHS or social services, so are often only available through compensation claims or self-funding.
- **Clinical psychologist:** aims to reduce psychological distress and enhance and promote psychological wellbeing. Many work as part of multi-disciplinary rehabilitation teams under specialist clinical neuropsychologists and often have particular skills in different forms of counselling. Unlike psychotherapists, psychologists use psychometric tests, interviews and other methods to assess and treat patients.
- **Clinical neuropsychologist:** 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.

- **Cognitive behavioural therapist:** a type of counsellor who uses cognitive behavioural therapy (CBT) to help people to overcome emotional difficulties. CBT works by helping people to change the way they think about themselves and the world and to alter problem behaviours. This is a particularly popular approach for people with brain injuries as it focuses on the here-and-now rather than the past.
- **Dietitian:** trained in using nutritional science to help people with health problems to make informed choices about diet and lifestyle.
- **Doctor:** many different kinds of doctors are involved in the care of people with brain injury. A consultant will co-ordinate the day-to-day medical care, carrying out examinations and prescribing medication while the patient is in hospital. General practitioners (GPs) are also important for people after brain injury as they are the first point of contact for most problems and can use their knowledge of a patient's medical history and other factors to assess, treat or refer to specialists.
- **Neurologist:** a medical specialist trained in the assessment, diagnosis and treatment of disorders of the brain and central nervous system.
- **Neuropsychiatrist:** a medical specialist who assesses and treats psychiatric disorders caused by acquired brain injury and diseases of the nervous system. Neuropsychiatrists often have experience in many aspects of the assessment and rehabilitation of brain injury and some run rehabilitation services. Sadly, there are a limited number of specialists in this field practising in the UK.

- **Neurosurgeon:** performs a range of surgical treatments for injuries and conditions affecting the brain and nervous system. A neurosurgeon will work in conjunction with the rest of the medical team and will often provide consultations with patients and their families.
- **Nurse:** plays a vital role in acute treatment, rehabilitation and residential care after brain injury. Nurses provide day-to-day care and help therapists to implement 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 multi-disciplinary team. On in-patient units and in the community there may be specialist nurses who take on specific roles, such as management of epilepsy or behavioural programmes.
- **Occupational therapist (OT):** helps 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 to compensate for any remaining problems. They help and advise on difficulties that may be encountered in the home environment, advise on any home adaptations that may be needed and are also involved in helping people to return to employment.
- **Physiotherapist:** helps people to regain the use of their muscles and joints after injury and helps with balance and movement problems.

- **Psychotherapist:** a UK Council for Psychotherapy member psychotherapist undergoes extensive training in working with a wide range of emotional distress and mental health issues. Psychotherapists are trained in more than one form of talking therapy and are different from counsellors in that counsellors can practice after relatively short training and tend to provide shorter term therapy.
- **Social worker:** provides practical advice and support on issues such as benefits, housing, transport and assistance at home. They are able to assess the support needs of brain injury survivors and their carers and help to access appropriate services. They are also trained to offer emotional support to individuals and their families.
- **Speech and language therapist (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.

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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/donate**, 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

Alternatively, you can make a donation of up to £10 by texting **Head01** and the amount you wish to donate **70070**.

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

Caring for someone with a brain injury

Richard Morris

This booklet has been written for the carers and family members of people with a brain injury. It provides practical suggestions to help you to cope with the early stages, manage the long-term challenges and find the support you need.

