Headway
the brain injury association

Caring for someone after brain injury

This publication has been written for people who are providing care for someone with a brain injury. It provides practical suggestions to help you cope with the early stages, manage the long-term challenges ahead and find the support you need.

This publication is also available as a printed booklet, which can be purchased from our online shop.

www.headway.org.uk
0808 800 2244

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Introduction

What is a brain injury?

A brain injury is any injury to the brain that has been sustained since birth. There are many possible causes including road traffic collisions, assaults, falls, strokes, brain tumours, meningitis, among others.

A person with a brain injury may need to be treated in hospital and undergo a period of rehabilitation afterwards.

A brain injury can cause long-term difficulties, and often also affects people around the brain injury survivor such as families and friends.

In this publication, we refer to people who have sustained a brain injury as ‘brain injury survivors’, ‘survivors’ or ‘your loved one’.

What are carers?

A carer is anyone who looks after a family member, partner or friend who needs help because of an illness or disability, and is not paid for doing so.

After a brain injury, it is often spouses/partners and other family members who take on caring roles to help the brain injury survivor with activities such as washing or dressing themselves,

staying safe, managing day-to-day activities and feeling emotionally supported.

Carers often have to make considerable changes to the way they live, such as spending less time with friends or reducing working hours. The changes can be difficult to adjust to.

In this publication, we refer to people who are providing care to the brain injury survivor as ‘carers’.

What information is in this publication?

This publication has been written for carers of brain injury survivors. It gives information on the different stages of brain injury and how you can support both the survivor and yourself through this journey. It also signposts you to other sources of information that might be helpful.

The information in this publication does not replace clinical guidance from medical professionals. You should always get advice from your GP or other suitably qualified professional for help with managing the effects of brain injury.

The organisations listed in this publication are provided for information purposes only. Their inclusion does not imply endorsement, recommendation, or approval by Headway. Users should make their own assessment of any organisation or service before engaging with them.

At the hospital

The period immediately following a brain injury can be a frightening and confusing time for many people. This might be your first experience of brain injury, and you might have lots of questions about what is going on and what to expect.

Regardless of the exact type of injury sustained, many people with a brain injury will spend some time initially being treated in hospital.

This section offers information on hospital systems and treatment at the early stage of brain injury, and gives guidance on how you can best support yourself and your loved one through this period.

Understanding hospital systems

Understanding the different stages of hospital treatment and care can be confusing, as they will vary depending on the type of brain injury that a person is being treated for. Treatment pathways will also vary depending on the severity of injury.

Mild brain injury/concussion
Someone with a mild brain injury/concussion might attend a hospital Accident and Emergency department (A&E) for a brief period of assessment and monitoring before being sent home. They should be provided with information on managing their symptoms upon discharge.

The person should be supervised for at least 24 hours after leaving hospital, and it may be that you are the person responsible for supervising them.

Our publication *Mild head injury discharge advice* contains guidance on symptoms for you to be aware of and directions for what to do should your loved one's condition worsen. More detailed information on this subject is available in our publication *Mild head injury and concussion*.

Moderate/severe brain injury
In the case of very serious injuries, a person will normally be taken to the nearest A&E, 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 that the person who has sustained the injury 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.

The hospital stage can sometimes be more distressing for family and friends than it is for the person with the injury (who might be unconscious or have no awareness or memory of this period).

You will probably want definite answers in the early stages, which medical staff often can't provide. Rest assured that, if this is the case, you are not being deliberately kept in the dark. Rather, it can be difficult to predict what the outcome of the injury will be. Clinicians might also be focused on their immediate priority of stabilising and managing your loved one's condition.

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.

Further information on hospital treatment and care is available in our publication *Hospital treatment and early recovery after brain injury*. If your loved one is in a coma or reduced state of awareness, information in our publications *Coma after brain injury* and *Prolonged disorders of consciousness after brain injury* might also be helpful.

How to help your loved one

It is normal to feel helpless when your loved one 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 loved one can take many forms and the following can all make valuable contributions.

- Communicate as much as possible with the nursing staff and therapy team. They will be able to suggest any appropriate ways for you to help and keep you informed of your loved one's condition.

- Organise visiting hours with a small number of family and friends that your loved one knows well. It is important to keep this number small so that you provide enough support without overwhelming them or causing disruption to their treatment and recovery. Having a small number of people visiting can also avoid confusion and maintain your loved one's dignity.

- Provide interesting things and stimulation for your loved one. Just talking to them about familiar things can help, as does showing them or reading to them from books or magazines of their interest.

- Help with your loved one's personal care under the advice and supervision of nursing staff.

- Keep your loved one's employer and friends informed of their situation.

- Do not feel like you have to talk for long periods when visiting – sitting quietly will offer reassurance and comfort, without overwhelming your loved one or causing fatigue.

How 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 suggestions are worth keeping in mind.

Lean on others

- Get help and support from professionals and services available at the hospital. This could include staff involved in your loved one's care, advisory services, a social worker or the hospital chaplaincy. You can ask at the hospital reception about services available if you are not sure who to contact.

- Contact our nurse-led helpline. The helpline team may be able to answer questions, explain what is going on, direct you to sources of support and offer emotional support. The helpline is available at 0808 800 2244 or helpline@headway.org.uk.

- Talk to other families on the ward in similar situations if they seem willing and comfortable with talking. Do remember that everyone's situation is different, and some families may not want to talk about their circumstances.

- Be very clear and assertive in telling people in authority what you want and what you need from them.

- Get practical help and support from relatives, friends and neighbours, such as getting lifts to and from the hospital,

asking them to look after young children or pets, or asking if they will cook a meal for you.

- Involve all the family in taking on household tasks so that you are not having to do this by yourself.

Rest, take breaks and make time for yourself

- Do not feel that you have to spend every moment sitting at your loved one'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.

- Try to make time for activities that can help you to relax, such as going for a walk or listening to music.

- Remember to eat a healthy, balanced diet and make time for exercise.

- See your GP with any health concerns of your own, including if you are having difficulties with sleeping or your mental health.

Make financial arrangements

- Talk things through with your bank in order to reschedule any debts and budget for your new circumstances.

- Organise personal finances and payment of bills. This can be a particular issue if your loved one 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.

- Start to research the welfare benefits that you may be entitled to when your loved one returns home. You might not need to apply for these, but it can be helpful to be aware of what financial support is available if you need it, for instance, if your loved one is unable to return to work. Be aware that if your loved one was on benefits before going into hospital then these may also be affected.

- Check any insurance policies your loved one has, particularly medical insurance.

- Talk to your loved one's employer to find out if they have an occupational pension which is initiated following serious injury.

- If your loved one has been in an accident, you may be able to take legal action against the person or organisation responsible. Although it may not be your priority at this stage, it is important to bear in mind that there may be time limits within which the claim needs to be made. You should seek advice from a solicitor with expertise in brain injury claims, for instance a solicitor from our Solicitors Directory. Our publication *Claiming compensation after brain injury* gives further information and guidance on this.

- Consider applying to become your loved one's deputy if they are lacking capacity and need best-interests decisions to be made on their behalf. You might already be their registered lasting power of attorney (POA). These arrangements will allow you to have access to bank accounts of your loved one and manage financial decisions on their behalf. Do note however that you should not rush into doing this. Deputyship can take several months to arrange, during which time your loved one's condition may change and the application might

no longer be appropriate. It also involves a fee. A letter from the hospital, confirming your loved one's inability to act for themselves, may be enough for some creditors/service providers to engage with you – however banks will not do so without POA/deputyship.

Make arrangements with employers

- Keep both your own and your loved one's employers informed about the situation.

- Check whether your employer has a scheme for compassionate leave. Your contract of employment or company handbook should contain details of this. Be aware that 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 to help them understand your situation.

- If the situation with your loved one is causing you to feel stressed or anxious to the point of needing to take time off work, consider asking your GP for a sick note so that you can take sick leave.

- Be aware that your loved one might 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 loved one will not be capable of returning to the job in any capacity.

- Consider contacting the Advisory, Conciliation and Arbitration Service (ACAS) for any concerns regarding employment matters. You can contact their confidential helpline on 0300 123 1100.

- If your loved one 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 and trusted friend or family member to deal with these matters. Your local Citizens Advice can offer assistance and signpost to local sources of support.

Keep records

- Try to keep details and records of key events, such as the date and time of the injury, the treatment your loved one receives and the professionals involved in their care. This might be useful at a later date, as it can be very difficult to remember everything accurately if it isn't first written down.

- Ask for a copy of any letters the hospital sends to your loved one's GP. These can provide valuable supporting evidence for benefits and compensation claims.

How we can help you

We offer a number of services that can be of help during this stage.

- *Freephone nurse-led helpline* – offers information, support and a listening ear to anyone affected by brain injury, including brain injury survivors themselves and carers. You can contact the helpline with questions you may have at this stage, or even if you just need to talk to someone about how you are feeling.

- *Emergency Fund* – provides one-off small grants to help brain injury survivors and their families cope with the financial

implications of brain injury. The Emergency Fund is often used by families to help with the costs of overnight accommodation and travelling to hospital to visit their loved one.

- *Independent charities and volunteer-led branches* across the UK – offering local support to people affected by brain injury, including carers. You can check what services your nearest charity or branch offers and get their contact details by visiting our website. Alternatively, our helpline can help you to find your nearest Headway.

- *Publications* – freely downloadable range of publications, offering information and guidance on various issues relating to brain injury.

- *Online communities* – a range of online communities offering information and support from others who have been affected by brain injury, including carers.

Coping with emotions

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.

- Coming to terms with a loved one's injury is a complex and ever-changing process. Feelings change rapidly at this time and it can be impossible to predict the stages of your emotional reactions.

- Don’t expect everything to make sense initially. Speak to other carers and families who have been through a similar situation, or other families on the ward. You can also use our services or online communities to connect with others who have been through similar experiences.

- It will be difficult to take information in at first (including information in this publication), but it will gradually start to sink in. Try to keep returning to any written information you have been given.

- Your GP may be able to refer you to counselling for emotional or psychological support if you are struggling with your emotions or mental health.

- The issues facing young children and their emotional reactions can be particularly challenging. If you have children, or there are children in the family, our publication *Supporting children when a parent has had a brain injury* might be helpful.

NHS support services

England
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 loved one’s treatment and help to arrange meetings with consultants. You can find details of your local PALS service at the hospital reception desk or website. Alternatively, you can search for a PALS service in your area on the NHS website at www.nhs.uk/service-search/other-health-services/patientadvice-and-liaison-services-pals.

Scotland

In Scotland, the Patient Advice and Support Service (PASS) can offer information and be contacted through your local Citizens Advice. Alternatively, visit www.pass-scotland.org.uk.

Wales

In Wales, Llais Wales can provide advice and support. For more information, visit www.llaiswales.org.

Northern Ireland

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). For more information visit www.pcc-ni.net.

Leaving hospital

Once your loved one is medically stable and any physical injuries have been treated, they may be ready to be discharged from the hospital. Where they go next will depend on what their ongoing needs are. Next steps can include being discharged to a rehabilitation unit, a residential or nursing facility, or returning home with arrangements made for ongoing support if needed.

Arranging a care plan

Before a discharge destination is decided, the medical team involved in your loved one's care should assess their health and social care needs. These should be outlined in a care plan by the healthcare commissioners and/or local authority.

A meeting should then be had in which the care pathway and its funding will be discussed. Social services staff should attend the meeting, together with hospital or rehabilitation staff, a continuing healthcare assessor, a social worker, close family members and possibly the GP. Further information on the funding of care is available in our publication *Assessment and funding of care after brain injury*.

A written discharge plan may then be produced with a copy to go to the GP. You can also request a copy of this.

You should be kept involved in discussions throughout this process. If you do not feel that you have been properly involved and you need support with raising this issue, it might be useful to have an independent advocate to help you. The relevant NHS patient support services (see previous section) should be able to help you with this.

Rehabilitation

Unlike most other cells in the body, brain cells do not regenerate when they are destroyed. However, this does not mean that no recovery can occur. The brain is somewhat flexible and is able to reorganise itself (to an extent) in order to regain lost function. This is known as brain 'plasticity'.

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

Rehabilitation can be delivered in a rehabilitation unit or in the survivor's home.

The rehabilitation team

Rehabilitation can include forms of therapy such as physiotherapy, occupational therapy, speech and language

therapy and neuropsychology. When several types of therapists work together as a team, this is known as a multidisciplinary team. Brain injury survivors often need a multidisciplinary team involved in their care, as many different functions can be affected by the injury.

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 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 vary. 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 make sure 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.

Further information about rehabilitation is available in our publication *Rehabilitation after brain injury*.

The role of the family in rehabilitation

Guidelines and recommendations for the treatment of brain injury survivors state that family and carers should be involved in discussions about care, including the setting of rehabilitation goals. Family involvement can also have a beneficial impact on the survivor's experiences. For instance:

- Family can be very helpful sources of information on the survivor's personal interests, preferences and aspirations, which can help to set person-centred rehabilitation goals.

- Family can help with encouraging survivors to practice using rehabilitation strategies and exercises, under guidance of professionals.

- Family provide invaluable emotional and practical support to survivors, which can contribute to keeping them engaged with rehabilitation.

Residential/nursing care

If your loved one no longer requires intensive rehabilitation, but isn't able to return home, they may be assessed as requiring long-term residential care.

Funding for this will be means-tested, so the survivor may need to contribute some of the costs themselves. However, if they are entitled to nursing care then this should be funded by NHS. Means-tested means that the amount of income and capital one has will be used to determine their eligibility for certain benefits.

There are residential care homes that 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.

There are a number of search and comparison websites for residential units and other care services, and some of these will have search filters for 'acquired brain injury' or specific types of brain injury such as stroke, head injury, etc to help you with your search.

You can also search for units from the websites of their respective inspecting and regulating bodies.

- In England, this is the Care Quality Commission: www.cqc.org.uk.
- In Scotland, this is the Care Inspectorate: www.careinspectorate.com.
- In Northern Ireland, this is the Regulation and Quality Improvement Authority (RQIA): www.rqia.org.uk.
- In Wales, this is Healthcare Inspectorate Wales: www.hiw.org.uk.

Headway Approved Care Providers

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

The units have been assessed against standards devised by Headway to ensure they provide appropriate specialist care for brain injury survivors with complex physical and cognitive impairment.

It is strongly recommended anyone wishing to use a care provider should visit at least two or three units before coming to a decision.

Returning home with care provision

At the discharge meeting, it might be decided that your loved one is ready to return home. However, it is important that you do not feel rushed into bringing them back home before you are ready. Try not to feel under pressure from anyone (including the survivor, who may be very keen to get back to familiar surroundings).

Only accept a proposed discharge date when you are certain that you have had the necessary assessments, that you have sufficient support and that all necessary equipment is in place at home.

Staged discharge

If it is decided that your loved one will return home, it might 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) before they are formally discharged from hospital.

Arranging for a staged discharge can help you to find out if any adaptations will be needed within the home while maintaining contact with the hospital or rehabilitation staff. An occupational therapist from the hospital, rehabilitation team or social services should also visit the home to assess any adaptations that may be needed.

Intermediate care

A brain injury survivor might be eligible for free care and support at home for a short period after they are discharged from hospital. This is known as intermediate care. It can include support from a paid carer, therapy goals being set, adaptations being made to the home or equipment being provided. Hospital

staff should discuss this with the brain injury survivor before they leave hospital.

A home assessment can also be arranged with an occupational therapist (OT) to identify any home adaptations that need to be made or equipment that needs to be accessed, such as handrails, ramps or perching stools. They can discuss this with a hospital OT before being discharged, or apply for a home assessment from their local council using the following link: www.gov.uk/applyhome-equipment-for-disabled.

Further information on intermediate care is available at www.nhs.uk/social-care-and-support/care-after-a-hospital-stay/care-after-illness-or-hospital-discharge-reablement.

Needs assessment

All brain injury survivors are entitled to a care needs assessment at any time if they need help to cope on a day-today basis. Therefore, even if they have been at home for a while, they can ask for an assessment.

A needs assessment can be completed to access help such as adaptations being made to the home, provision of equipment, access to day centres and practical help from a paid carer.

Local authorities throughout the UK should complete an assessment for anyone who needs it. The brain injury survivor's wishes and preferences should be taken into account when deciding on the services they receive.

Carers are also entitled to assessments to identify their needs – this is called a carer's assessment, and more information on this is available further on in this publication.

Becoming a carer

When your loved one comes home there may be many new challenges to face. They will be adapting to their new circumstances and may still be processing the experiences they have just been through in hospital. You will also be adapting to your new role and routine as a carer, which can come with its own challenges.

However, with the right support in place, things can be made easier.

This section outlines your rights and entitlements as a carer, and some key practical issues you might need to think about.

Carer's assessments

A carer's assessment looks at your needs as a carer and whether you are entitled to services to make caring easier for you. Services can include:

- help with housework and looking after the brain injury survivor;
- equipment and adaptations to the home;
- emotional support;
- breaks from caring.

You can contact your local authority to request an assessment (for contact details visit www.gov.uk/find-your-local-council).

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 loved one is still in hospital, so that you have services in place when they come home.

There are a number of issues you might want to think about raising in the assessment, such as:

- yours and the survivor's housing situation;
- any additional and relevant health issues (either your own or the survivor's);
- the impact of your caring role on work;
- the impact of your caring role on your relationships (not just with the survivor);
- your feelings about providing care;
- any other concerns for the future;
- other caring responsibilities e.g. children, parents.

Further guidance is available on the Carer's UK website at www.carersuk.org/help-and-advice/practical-support/carers-assessment/.

After the 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.

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.

Carer's emergency schemes

It is very important to know that your loved one for is looked after should anything happen to you unexpectedly. Many areas run carers emergency schemes which can provide a pre-

arranged support network and plan if you are suddenly unable to provide care.

The availability and nature of the schemes vary throughout the UK. You should discuss registering with your local scheme during your carer's assessment. You can also contact your local social services team to discuss at any time.

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 include 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.

Benefits and entitlements

There are a number of benefits and other types of financial support that you may be entitled to, depending on yours and the survivor's personal circumstances.

Below are some of the benefits and schemes currently available.

Benefits and entitlements change over time and you should always check the UK government website at www.gov.uk for the latest information.

Carer's Allowance

You might be entitled to Carer's Allowance (CA) if you are 16 years old or over and are looking after the survivor for more than 35 hours a week. Entitlement to CA can lead to an increase in some benefits, through the inclusion of the Carer's Premium. Do note that if someone else looks after the same person, only one of you can get CA.

Carer's Credit

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

Grants

Financial 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, the Discretionary Assistance Fund (for Welsh residents) and Community Care Grants. The organisation Turn2Us offers a grant search function on their website at www.grantssearch.turn2us.org.uk.

Transport schemes

The Motability scheme helps people on certain welfare benefits 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 (such as yourself) as their driver. The Motability Scheme also makes scooters and powered wheelchairs available. More information is available from Motability at www.motability.co.uk.

The Blue Badge parking 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.

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. Bus, coach and airline companies might also offer discounts for carers.

There are also schemes available to help with transport to appointments for the person you are caring for. Hospitals and rehabilitation centres provide transport for patients, and this will often extend to carers as well.

If your loved one 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. Many local councils have their own schemes, so check with yours for details. For example, discretionary grants may be available for the costs of hospital visits if you are in receipt of certain benefits.

Leisure

The Cinema Exhibitors' Association Card 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 about this.

The book Rough Guide to Accessible Britain provides information on holiday destinations for disabled people. It is freely downloadable from www.motability.co.uk/news-andevents/rough-guide-to-accessible-britain.

Helping your loved one to apply for benefits

Your loved one might be entitled to claim welfare benefits. Applying to benefits will require filling out forms, which your loved one might struggle to do by themselves and need help

with. Here are some points to consider if you are helping them with this.

- Consider contacting your nearest Headway, as some of these can help with applying for benefits. You can locate your nearest one by visiting www.headway.org.uk/supporting-you/in-yourarea or contacting our helpline.

- Contact our nurse-led helpline, as they can signpost to specialist sources of support.

- There are organisations that specialise in offering information on benefits, such as Turn2Us (www.turn2us.org.uk) or Entitled to (www.entitledto.co.uk).

- 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.
- Don't forget to keep copies of medical records, letters from the GP or hospital, and your own notes, as these can be valuable accompanying evidence for claims.

Employment

The following pieces of legislation protect the rights of people (including 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.

If you are concerned that you aren't being treated fairly at work due to your caring responsibilities, the Advisory, Conciliation and Arbitration Service (ACAS) helpline can offer free, confidential advice on 0300 123 1100.

Administering medication

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

It is extremely important to administer the correct medication at the correct dosages, in the correct way. The following should be noted:

- Any responsibility for administering medication that you have been given should be mentioned at the discharge meeting and during a carer's assessment.

- Make sure you are completely confident about what you have to do, and any potential side-effects of the medication, before your loved one is discharged home. If you have any concerns or have forgotten anything, ask.

- Get very clear, written instructions about dosages and the times to administer them.

- If your loved one has returned home and you both still have questions about their medication, you should start by talking to their GP and/or pharmacist as soon as possible.

- Try to arrange professional support if possible. For instance, you might be able to arrange home visits from the district nurse to help.

- If your loved one will be responsible for administering their own medication, there are a number of products available which can help, especially for people with memory problems. For instance, 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.

Making decisions on your loved one's behalf

It should always be assumed that someone has capacity to make their own decisions, unless proven otherwise. However, some brain injury survivors may lose their capacity to make certain decisions, in which case someone can be legally appointed to make decisions on their behalf in their best interests.

If your loved one lacks capacity to make certain decisions, for instance regarding their finances, the Court of Protection should be applied to so that you, a family member, friend or professional can be appointed to make decisions on their behalf. This will need to be done under the framework of the Mental Capacity Act (2005). Decisions made on someone's behalf are situation specific and must always be made in the person's best interests.

The issues surrounding mental capacity are complex. Further information is available in our publication *Mental capacity:*

supporting decision making after brain injury, and by contacting our nurse-led helpline.

Relationships

Brain injury can change the dynamics of families and relationships in different ways.

Changes to roles and responsibilities

Responsibilities within the family can change and this can be very hard for everyone to get used to at first. For example, a survivor who was previously the 'breadwinner' of the family may no longer be able to work, and a partner who previously did not need to manage bills may now become responsible for this.

Older children may need to take on carer roles, such as helping out more with chores or taking on the responsibility of looking after younger siblings or pets.

There may also be changes in how the survivor and their partner/carer feel about their roles in the relationship, especially if the carer is needing to help the survivor with activities such as washing and dressing.

Changes to feelings

The survivor's behaviour may be different after their injury, or they may no longer have the same interests as they once did. This can lead to changes in the relationship if the carer/partner no longer feels that they are with the same person that they originally chose to be with.

Young carers may feel confused and hurt that their parent or relative is suddenly so different. Such changes in relationships can cause challenges, and there can often be a lot of frustration

and feelings of loss. However, there can also be positive changes and a strengthening of relationships. For example, the survivor might now get more time to spend with their family, and the bond between them could strengthen as a result.

In some cases, the changes may only be temporary, and might be a natural response to the survivor having gone through a life-changing experience, which can take time to process and adjust to. It is important to keep communication open and honest with one another, and work with the survivor's therapists on family and relationship issues.

Changes to sexual relationships

Changes in sexual functioning after brain injury can be difficult to talk about or ask for help with. However, sex is a normal and natural part of life, and it is important to get support if this is an issue for either the brain injury survivor or their sexual partner.

It helps for both partners to talk things through honestly and openly. You may wish to do this 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 Relate (www.relate.org.uk).

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 our publication *Sex and sexuality after brain injury*.

Changes to friendships

As a carer, it is very important to feel well supported and assured that you have trusted people who you can talk to about

how you are feeling. Friends are an important source of support, but it is possible that your caring duties make it difficult to find the time to stay in touch with others.

Being honest with your friends about your situation and keeping them updated can help to remove any uncertainty about why you are not keeping in touch or seeing them as regularly. Your friends might not know about brain injury, and while they might support you at the hospital stage, they might be less likely to understand the longer-term impact of brain injury when your loved one returns home.

Help your friends to understand yours and your loved ones' experiences by sharing information on brain injury, such as other Headway publications.

Consider asking for activities to be adapted to accommodate for your new circumstances. For instance, consider asking friends to come and visit you at home if this is more convenient, or to reschedule activities to a time that better suits your new routine.

Don't be afraid to ask for practical support from close friends, such as help with grocery shopping or cooking meals.

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 loved one more effectively.

You may find that attending support groups such as your local Headway allows you to meet other carers in similar situations who you can form friendships with.

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 can be stressful and time consuming and it can be easy to let yourself stop making the effort to eat healthily and engage in exercise. However, being fit and healthy helps you to deal with stress and cope better with everyday life.

Maintaining a healthy lifestyle can counter the 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 loved one's care

package and any services provided by your own carer's assessment (see previous section Becoming a carer).

There are a number of options available for respite care:

- Many residential and nursing care homes can provide short-term care for a brain injury survivor.
- 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 loved one and yourself.
- It is often possible to arrange home support for your loved one in order to go away on holiday yourself.

Some social services departments operate voucher schemes to provide respite care. You can also use direct payments to pay for respite care.

Carer support groups

Often the best source of support is other carers in a similar situation to yourself.

Many of Headway's local services 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.

If you are not able to attend a local Headway, you can find support from other carers through our online communities. More information on these services is available at www.headway.org.uk/supporting-you.

Specialist carers' organisations, such as Carers UK or Carers Trust, offer support groups and services in many areas of the

UK. Your local council should be able to signpost to other local groups.

Young carers

Following your loved one'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 loved one 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.

- 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/what-we-do/ourwork/supporting-young-carers for more information.

- Barnados runs projects across the UK which support young carers and their families in a variety of ways. Visit www.barnardos.org.uk for more information.

- Some of Headway's local services 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.

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.

You can make arrangements in advance by having honest and open discussions with other relatives and close friends about whether they would be willing to take on any aspect of caring in the future. Find out about local services and facilities that might be accessible to your loved one in the future, and keep important information that you need to pass on in a safe place.

Our publication *Ageing carers of brain injury* survivors offers information about this and practical suggestions of how to make future arrangements.

Conclusion

Becoming a carer can be very difficult. Caring for someone 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 loved one 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 loved one and yourself. Hopefully this publication has helped you to identify your particular areas of need and access sources of support to address them.

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We hope that this has been a helpful resource. Please consider sharing your feedback with us by scanning the QR code or by visiting our publication feedback survey https://uk.surveymonkey.com/r/hwpublications.

Learn more and support our work at www.headway.org.uk/get-involved.

This information was last reviewed in 2025.

We're here to listen.

If you need support, or have a question about brain injury, contact our free nurse-led helpline:

0808 800 2244
helpline@headway.org.uk

0115 924 0800 | enquiries@headway.org.uk
www.headway.org.uk

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Old Basford, Nottingham, NG6 8SF

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