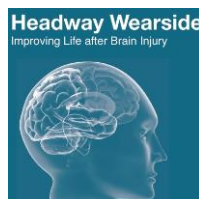


Family Information Pack: Part 1 – General Information for all areas

The information pack has been developed following consultation with families by Julie King, Headway Wearside Family Support Officer based at Walkergate Park.

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Brain injury doesn't just affect individuals; it can transform the lives of entire families. Here are some tips and information that can help you cope when caring for someone who has had a brain injury:

1. General Tips

- a) Be flexible: recovery from a brain injury can take time and be unpredictable so try not to be rigidly tied to how things ought to be but try to embrace change and view it as a challenge.
- b) Communicate openly and honestly: try to directly express emotions both positive and negative and recognise your own needs, those of others within the family as well as those of the person you care for. Caring can be stressful at times so do not be afraid to ask questions about the brain injury or raise concerns you have.
- c) It can be helpful to learn more about a brain injury and its impact. Headway UK's website has a wealth of helpful information including a leaflet about caring for someone for a brain injury. Also, your local Headway will be able to support you and help you find answers to any questions you have.
<https://www.headway.org.uk/about-brain-injury/>

2. Managing someone else's affairs

There are different ways of managing someone's affairs. How this is managed will depend on whether the person you are looking after can currently make decisions for themselves (which is called having mental capacity) or whether they are unable to make decisions for themselves (which is called lacking mental capacity).

a) Benefits

The benefits system – This is complicated, so it is important to get a check to make sure that you and the person you care for are getting the benefits you are entitled to. This may include PIP, ESA, Attendance Allowance or a reduction of your Council Tax. There are national helplines, and each area has local organisations that can offer advice which may include, Citizens Advice Bureau, Age UK.

You can use an independent, free and anonymous benefits calculator to check what you could be entitled to. This will give you an estimate of:

- the benefits you could get
- how much your benefit payments could be
- how your benefits will be affected if you start work or increase your hours
- how your benefits will be affected if your circumstances change - for example, if you have a child or move in with your partner

Information on income-related benefits, contribution-based benefits, Universal Credit, tax credits, Council Tax Reduction and Carer's Allowance can be found at:

<https://www.gov.uk/benefits-calculators>

It can be a good idea to get help to fill in benefit forms and if possible, by someone who knows about the impact of a brain injury so that issues with executive functioning and fatigue can be fully explained. Organisations who may be able to help with this include some Headway branches/groups, your local Citizens Advice Bureau, branch of Age UK.

More information about benefits can be found at:

- www.gov.uk
 - <https://www.gov.uk/pip>
 - <https://www.gov.uk/employment-support-allowance>
 - <https://www.gov.uk/universal-credit>
 - <https://www.gov.uk/statutory-sick-pay>
 - <https://www.gov.uk/browse/working/state-pension>
- <https://www.citizensadvice.org.uk/benefits/>
- <https://www.ageuk.org.uk/information-advice/money-legal/benefits-entitlements/>
- <https://www.carersuk.org/help-and-advice/financial-support/help-with-benefits>

You can apply for the right to deal with the benefits of someone who cannot manage their own affairs <https://www.gov.uk/become-appointee-for-someone-claiming-benefits>

- b) Lasting Power of Attorney (LPA) – for a person over 18 who has capacity
An LPA is a legal document that lets someone (the 'donor') appoint one or more individual (known as 'attorneys') to help them make their own decisions or make decisions on their behalf.. There are 2 types of LPA one for health and welfare and the other for property and financial affairs.

<https://www.gov.uk/power-of-attorney>

- c) Court of Protection – when a person lacks capacity
If your loved one is unable to make their own decisions and needs help to manage more than just their benefits, you could apply to the Court of Protection to become their appointed deputy (if there is no lasting power of attorney already in place). This means that you will have the authority to make certain decisions on their behalf.

<https://www.gov.uk/become-deputy>

There are two types of court appointed deputy:

- court appointed deputy for property and financial affairs – which covers things such as bank accounts, paying bills, benefits and pensions and selling a home.
- court appointed deputy for personal welfare – which covers things such as medical care and social care.

d) Third Party Mandate

If your family member has not set up an LPA, they can still give consent for you to speak to their GP on their behalf by completing a third-party consent form where they can set out who the GP is authorised to speak to.

3. **Carers Assessment.**

A Carers Assessment from Adult Social Care gives you the chance to talk about the impact of being a carer on your life, ways of managing your caring role and finding support services (including breaks). It's not an assessment of how well you look after the person you care for it's about helping you and is something you're legally entitled to.

Even if the person you care for does not receive service from Adult Social Care you can still have a Carers Assessment and if you are assessed as having eligible needs, you may receive a Carers Personal Budget which can be used to help you pay for a things to maintain your wellbeing for example a break, equipment, activities that will make your life easier such as a computer to help you save time by doing tasks such as banking and paying bills online.

<https://www.carersuk.org/help-and-advice/practical-support/carers-assessment/>

4. **Carers Emergency Plan**

Many carers worry about what might happen if they are unwell. It is worth spending a bit of time gathering and writing down information about the needs of the person you care for, key contacts etc so that everything is in one place. This can give you peace of mind as it can be referred to in an emergency. A template document can be found in Appendix A.

5. **Know your rights**

'Looking after Someone' is a guide produced by Carers UK. It provides an overview of everything you need to know, from your rights to practical tips and financial support options. <https://www.carersuk.org/help-and-advice/guides-and-tools/looking-after-someone-guide/>

Don't be afraid to voice your concerns and needs. Often when you're caring for someone you become that person's advocate, and you may have to help them get their voice heard. This doesn't come naturally to everyone – it could be that you find talking to professionals about your loved one's care really difficult. Carers UK's guide on self-advocacy discusses skills you need to speak up for yourself and the person you care for. <https://www.carersuk.org/help-and-advice/guides-and-tools/being-heard-a-self-advocacy-guide-for-carers/>

6. Home adaptations

If you need to adapt your home to make it suitable for the person you care for you may be able to get a Disabled Facilities grant to help with the costs. Find out more at <https://www.gov.uk/disabled-facilities-grants>

7. Travel and Leisure

a) Blue Badge

This provides a range of parking benefits for disabled people who have difficulty walking, allowing them to park closer to their destination.

<https://www.gov.uk/apply-blue-badge>

b) Motability Scheme

A brain injury survivor can exchange their qualifying mobility allowance for a brand-new car, Wheelchair Accessible Vehicle, scooter or powered wheelchair, so they can enjoy more freedom and independence.

<https://www.motability.co.uk/how-it-works/>

c) Disabled Persons Bus Pass

You can contact your local council to find out who issues disabled bus passes in your area as part of the English National Concessionary Travel Scheme.

<https://www.gov.uk/apply-for-disabled-bus-pass>

d) Disabled Persons Railcard

With this card you can get 1/3 off adult train travel.

<https://www.disabledpersons-railcard.co.uk/>

e) Leisure Activities

Section 11 has details of information website(s) where you can find information about activities in your area.

8. Accessible holidays and breaks

After a brain injury, planning a holiday can involve a lot more planning. Headway UK has useful information on its website, to help you including details of insurance companies who offer insurance to people with a disability.

<https://www.headway.org.uk/about-brain-injury/individuals/practical-issues/holidays-and-travel/>

Here are some websites that offer accessible breaks/funding information:

- Access at Last: Offers wheelchair accessible holidays
www.accessatlast.com/
- Calvert Trust: Offers a number of accessible activities through a network of centres www.calvert-trust.org.uk
- Disabled Access Holidays.com: Offers assistance with transport, accommodation and booking holidays for people with a disability
www.disabledaccessholidays.com/default.asp

- Motability - Rough Guide to Accessible Britain: Offers information about accessible holiday destinations across Britain.
<https://www.motability.co.uk/news-and-events/rough-guide-to-accessible-britain/>
- Revitalise: Provide breaks and holidays for people with disabilities
www.revitalise.org.uk/respice-holidays/
- Tourism For All: Offers directories of accommodation, things to do and food and drink to help with planning an accessible holiday
<https://www.tourismforall.co.uk/>
- Turn2Us: Offers a grant search tool to help with finding grants to provide financial assistance with arranging holidays <https://grants-search.turn2us.org.uk/>

9. **Keeping you and the person you care for safe**

a) Brain Injury Identity Card

The Headway Brain Injury Identity Card is designed to help police officers and staff more easily identify brain injury survivors and ensure that they receive an appropriate response and support. The card can also provide brain injury survivors with added confidence in everyday social scenarios. Each card is personalised, helping the card holder to explain the effects of their brain injury and request any support they may need.

<https://www.headway.org.uk/supporting-you/brain-injury-identity-card/>

b) Fire and Home Safety Check

Many fire services can carry out a home safety check. Firefighters can visit your home and offer detailed advice on safety tailored specifically to your needs. Contact the fire service in your area for more information.

c) Priority Services Register

Utility and telephone providers operate a register, of vulnerable customers who will receive priority service including:

- advanced notice of scheduled power cuts and priority support in an emergency.
- identification and password scheme
- nomination of another person to receive communications on their behalf

<https://www.ofgem.gov.uk/information-consumers/energy-advice-households/getting-extra-help-priority-services-register>

Contact your utility or telephone provider to register.

9. **Looking After Your Own Health and Wellbeing**

It is easy to let your own needs take a back seat while you are preoccupied with the health and wellbeing of the person you care for. Caring can be rewarding but can also be emotionally and physically demanding. It can feel as though there is very little time for you to take a breather however, finding moments to relax and destress can make a huge difference to your wellbeing. Remember that

your health and wellbeing are equally as important as the person you look after - if you aren't well yourself then how will you support them?

- Be realistic and honest with yourself about what you can manage once your loved one is discharged. If additional care is needed, it may require a review once you have settled into your caring role, and you have a better understanding of what is involved. If you find that things are more challenging than you had hoped, even if support has been organised for you contact Adult Social Care, the Care Manager, or team who is delivering the care.
- Take a regular break. There can be so many tasks to juggle when looking after someone, it's easy to get run down and burn out. Breaks are vital for your own wellbeing and quality of life. Having a regular break will help you to keep going. Think about the kind of break that you need and what kind of alternative care the person you are looking after needs.

You may find yourself worrying and struggle to get enough sleep or rest, especially if you are helping to look after someone during the night. You may wish to discuss this with your GP. The NHS website has some helpful suggestions: <https://www.nhs.uk/live-well/sleep-and-tiredness/>

Carers UK also has useful tips: <https://www.carersuk.org/help-and-advice/your-health-and-wellbeing/getting-enough-sleep/>

- If you have trouble switching off, you may find techniques such as mindfulness or relaxation helpful. Mindfulness is simply being fully present or engaged in the 'now', being aware of where we are and what we're doing, so that we are not overly reactive or overwhelmed by what's going on around us. <https://www.nhs.uk/search/results?q=mindfulness>
<https://www.nhs.uk/search/results?q=relaxation>

Many carers find Tai Chi or Yoga helpful. In section 11 you will find information website that can help you find local activities.

- Be open to accepting support from others, you may have friends and family who are happy to help if asked. If the person you look after is eligible for social care support, then you may be able to get regular respite as part of their care plan. Speak to Adult Social Care and ask that replacement care to give you a regular break is written into their care and support plan (if eligible).
- Get support from other carers – It can be helpful to share experiences with others who are in a caring role. Most local Headway or carers' organisations offer peer support groups. Headway (national) offers online discussion forums. <https://www.headway.org.uk/supporting-you/online-communities/>
- You could let your GP know you are a carer. The NHS are keen for GP practices to keep a record of patients who are carers so they can look after

your health and wellbeing. They will be able to let you know about schemes such as free flu jabs and other health initiatives that may help you to maintain your health.

- Looking after your mental wellbeing - If you are struggling support is available. You could speak to your GP, or you can contact your local NHS Talking Therapies service. <https://www.nhs.uk/service-search/mental-health/find-an-NHS-talking-therapies-service/>

If you require help urgently you can seek help from an NHS initial Crisis Team: Details can be found in section 2.

Other organisations that can help support mental wellbeing can be found in section 14.

10. **Employment Issues**

Juggling working and caring can be a challenge. Without the right support, the stress and pressure can lead people to reduce their hours or even give up work. Before deciding to give up work, it's worth seeing if you can improve your situation. It can be useful to ask your employer if they have a carers policy or other support that could help you as a carer. You have various rights in relation to work:

- 'Statutory rights', which everyone has.
- 'Contractual rights' as set out in your contract of employment, which can be more generous than statutory rights e.g. additional holiday.
- The Carer's Leave Act 2023 will come into force on 6 April 2024. It gives employees in England, Wales and Scotland a statutory right to take up to one week of unpaid leave to care for a dependent. <https://www.gov.uk/time-off-for-dependants>
- Flexible working - All employees have the legal right to request flexible working.. From 6 April 2024 employees will be able to request flexible working from their first day in a new job. <https://www.gov.uk/flexible-working>
- The Equality Act 2010 provides carers with protection from some forms of discrimination. For example, employers and providers of goods and services must not treat carers less favourably than those without caring responsibilities.

If you or the person you care for is having issues at work Acas - the Advisory, Conciliation and Arbitration Service may be able to help. They offer free, impartial advice on any work-related problem or question you have; what the law says and how it relates to you; good practice at work; your options, including any risks and benefits. Their website has a lot of useful factsheets and resources.

<https://www.acas.org.uk/>

Helpline: 0300 123 1100. Monday to Friday, 8am to 6pm.

11. Online Sites which offer freebies/low cost items or discounts

Discounts for Carers

This site offers a range of discounts to unpaid carers & care workers.

<https://discountsforcarers.com/>

Money Saving Expert

Aims to provide the best MoneySaving guides, tips, tools and techniques.

<https://www.moneysavingexpert.com/>

Freecycle

A grassroots, non-profit movement of people who are giving and getting items for free in their own towns. The aim is to promote reuse and keep goods out of landfills. Membership is free.

<https://www.freecycle.org/>

Gumtree

A site for free classified ads.

<https://www.gumtree.com/>

Credit Unions

A credit union is a self-help co-operative whose members pool their savings to provide each other with credit at a low interest rate. You can get information about credit unions from the Association of British Credit Unions (ABCUL) website: www.findyourcreditunion.co.uk or the ACE Credit Union Services website: at www.acecus.org

12. National Organisations that offer practical and emotional support

Headway UK

A charity which aims to promote understanding of all aspects of brain injury, whatever the cause including trauma, stroke, infection, tumour etc They provide information, support and services to survivors, their families and carers. Their services include:

- an advice and information helpline
- fact sheets and resources
- a register of approved solicitors and care providers
- online discussion forums
- a directory where you can find information about local support groups

Free Nurse led support helpline: 0808 800 2244

Email: helpline@headway.org.uk

Website: <https://www.headway.org.uk/>

Carers UK

A national charity which aims offers unpaid carers expert information and guidance and campaigns to promote their rights. Their services include:

- an advice and information helpline
- fact sheets and information resources
- online groups, physical activity and wellbeing videos
- a directory of local support services for carers

Telephone: 0808 808 7777

Website: <https://www.carersuk.org/>

Carers Trust

A network of local centres providing advice and support to carers.

T 0300 772 9600

carers.org

Day One Trauma Support

A charity that offers practical and emotional support to help someone make the best possible recovery following a major physical trauma.

<https://dayonetrauma.org/>

Brain Tumour Support

A charity is that provides support for anyone affected by any type of brain tumour, at any point from diagnosis and for as long as support is needed.

Telephone Helpline: 01454 422 701

Website: <https://www.braintumoursupport.co.uk/>

The Brain Charity

Offer help and support to people across the UK who have more than 600 different neurological conditions.

<https://www.thebraincharity.org.uk/>

The Brain Tumour Charity

Provides brain tumour support and information.

<https://www.thebraintumourcharity.org/>

Stroke Association

A national charity that supports people affected by stroke. Provides advice and information via a helpline and an online search facility to find local support groups.

Telephone: 0303 3033 100

Website: <https://www.stroke.org.uk/>

Meningitis Now

A national charity that supports research and provides specialist support to those affected by Meningitis. They employ a Community Support Officer who covers the North of England.

Telephone: 0808 80 10 388

Email helpline@meningitisnow.org.

Website: <https://www.meningitisnow.org/>

MS Society

A national charity which funds world-leading research and campaigns for the rights of those affected by MS. They offer a helpline, and their website has a range of useful resources and information about local support groups.

Telephone: 0808 800 8000. Monday to Friday, 9am to 7pm except bank holidays.

Website: <https://www.mssociety.org.uk/>

Huntington's Disease Association

A national charity which aims to improve care and support services for people with Huntington's disease, educate families and professionals, and champion people's rights. They offer a helpline, and their website has a range of useful resources and information about local support groups.

Telephone: 0151 331 554. Monday to Friday, from 9am to 5pm.

Website: <https://www.hda.org.uk/>

13. Advice and Information Organisations

Age UK

Age UK offer older people a range of help and support including a national advice line

0800 678 1602. They produce a range of very useful fact sheets.

<https://www.ageuk.org.uk/services/information-advice/guides-and-factsheets/>

Most areas have a local Age UK that offer a variety of services including advice/information and activities.

Citizens Advice

A network of independent charities who offers confidential advice online, over the phone, and in person, for free. They offer benefits advice, give advice on consumer rights on their consumer helpline, support witnesses in courts through the Witness Service and give pension guidance to people aged over 50.

<https://www.citizensadvice.org.uk/>

14. Mental health and Wellbeing

Anxiety UK

<https://www.anxietyuk.org.uk/>

Mental Health Foundation

<https://www.mentalhealth.org.uk/>

Mind

<https://www.mind.org.uk/information-support/local-minds/>

Rethink Mental Illness

<https://www.rethink.org/>

Samaritans

Helpline 24 hours a day, 365 days a year.

Call 116 123 for free

<https://www.samaritans.org/>