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association

fact sheet

Caring for someone with a brain injury

5. 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' rights to an assessment

- **The Carers and Disabled Children Act (2000)** states that carers aged 16 or over, who provide a “regular and substantial amount of care” for someone aged 18 or over, have the right to an assessment of their needs as a carer. If there is more than one carer providing regular care in the household, they are all entitled to an assessment. Occasionally, a 16 or 17-year-old who cares for someone for a limited period may be entitled to an assessment.
- **The Carers (Equal Opportunities) Act (2004)** places a duty on local authorities to ensure that all carers know that they are entitled to an assessment of their needs and to consider a carer’s outside interests when carrying out an assessment. The Act also promotes better joint working between councils and the NHS to ensure better support for carers.

Carer's assessment

The legislation outlined above states that you are entitled to an assessment if you provide a “regular and substantial amount of care”, but there is no specific definition of this term. Therefore, even if you only look after a friend for a couple of hours a week, it would still be worthwhile applying for a carer’s assessment.

A carer’s assessment allows social services to assess your situation and decide if you are entitled to any services that could make caring easier for you.

You are also entitled to an assessment if you intend to care for someone, so it is a good idea to have the assessment while your relative is still in hospital in order to have the support you need in place before they come home. In order to do this, ask to speak to the hospital social worker.

The assessment will be carried out by a social worker and can be in your home or the home of your relative. The assessment is all about providing for your needs as a carer, rather than considering your relative’s needs.

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Applying for a carer's assessment

In order to apply for a carer's assessment you can contact your local council's social services department (contact details can be found in the local telephone directory). You can also find more information and apply online on the government website at www.direct.gov.uk.

There are a number of issues you might want to think about raising in the assessment. You may find it helpful to use Headway's 'Carer's assessment checklist' factsheet to prepare.

Social care support for carers

After an assessment, social services will develop a care plan, which should include the support and services that you have been assessed as needing. The services can be managed by the local authority or, alternatively, you can opt to receive direct payments, which can be used to manage and pay for the services yourself.

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.

Remember, while local authorities have a duty to provide services for the person you care for if their need is sufficiently high, they are only deemed to have 'powers' to provide services for carers. This means that they are not legally obliged to do so.

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

Making a complaint about social services

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 or challenge the amount that is being charged for services. See the Headway factsheet 'Making a complaint about social services' for more details.



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Benefits and entitlements

There are a range of benefits and other forms of financial support that you may be entitled to. 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 rate of the Disability Living Allowance (DLA) Care Component. You must be providing care for at least 35 hours per week. Claims can be backdated 3 months. Entitlement to CA (whether paid or not) can lead to an increase in some other benefits, through the inclusion of the Carer's Premium. This can apply to Income Support, Income-Related Employment and Support Allowance, Housing Benefit and Council Tax Benefit. Advice should be sought before you claim CA to see if your relative's benefits might be adversely affected.
- **National Insurance contributions and Pension Credit** - If you do not earn enough to pay National Insurance contributions you can still build up an entitlement to a State Pension if you are entitled to Carer's Allowance, even if you don't receive it because you get another benefit at the same or higher rate.
- **Community Care Grants** - You may be eligible for a Community Care Grant if you are getting certain benefits and you need financial help to ease exceptional pressure on your family. The amount will depend on your circumstances and will not affect any other benefits you receive.
- **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.

Vehicles and transport

- **The Motability Scheme** - This scheme helps people on the Higher Rate Mobility Component of DLA 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 0845 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.
- **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.



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- 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 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.

Leisure

- Cinema Exhibitors' Association Card - This is a national card for people who receive DLA or are registered blind, which entitles the holder to one free ticket for a person accompanying them to the 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 available from www.accessibleguide.co.uk.
- The Headway factsheet Holidays and Travel 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 on all the above, please visit www.direct.gov.uk.

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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 Citizens Advice Bureau and the local authority's welfare rights officer are also good sources of support, but they may not have specific experience with brain injury.
- Headway's factsheet Guide to the DLA claim form is an excellent reference when applying for DLA.
- Copies of medical records, letters from the GP or hospital, and your own



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notes, can be valuable accompanying evidence that can be attached to claims.

For further sources of support and information see the 'Useful organisations' factsheet.

Employment

- **The Employment Act (2002)** gives you a legal right to ask your employer for flexible working hours if you are caring for an adult who is a relative or who lives at the same address as you. However, there is no legal obligation for the employer to grant this request, although they must give a valid business reason for refusing.

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.

There are a number of organisations that can provide information on employment, education and funding if you intend to return to employment or education after a break. Contact the Headway helpline for more information.

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



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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 (2007). 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 'A guide to the Mental Capacity Act' and by contacting the Headway helpline.

This information has been adapted from the Carers UK website at www.carersuk.org.

This factsheet is adapted from the Headway booklet 'Caring for someone with a brain injury', which includes more information and case-studies.

To discuss any issues raised in this factsheet, or to find details of our local Groups and Branches, please contact the Headway helpline free of charge on 0808 800 2244, or by email at helpline@headway.org.uk. You can also find more information and contact details of Groups and Branches on our website at www.headway.org.uk.

Headway produces a range of booklets and factsheets covering brain injury related issues. Booklets can be ordered from www.headway.org.uk/shop.aspx or by telephone on 0115 924 0800. Factsheets are freely downloadable from the website.

Brain injury survivors and carers can receive free copies of appropriate booklets from the helpline.

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